

**“A Study of Psycho-Social Barriers of low Adherence in HIV
Therapy and social work intervention with reference to
ART centre, Indira Gandhi Government
Medical College , Nagpur.”**

**A dissertation submitted to the R.T.M. Nagpur University in partial
fulfillment of the requirement for the degree of
Master in philosophy (Social Work)**

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and social work intervention with reference to
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Medical College, Nagpur."

A Dissertation submitted to the R.T.M. Nagpur University in
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2010-2011

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A Study of Psycho-Social Barriers of HIV Infection in HIV Therapy

and social work intervention with reference to

AIDS control, India (Central Government)

Medical College, Nagpur

A dissertation submitted to the K.T.M. Nagpur University in

partial fulfillment of the requirement for the degree of

Master in Philosophy (Social Work)

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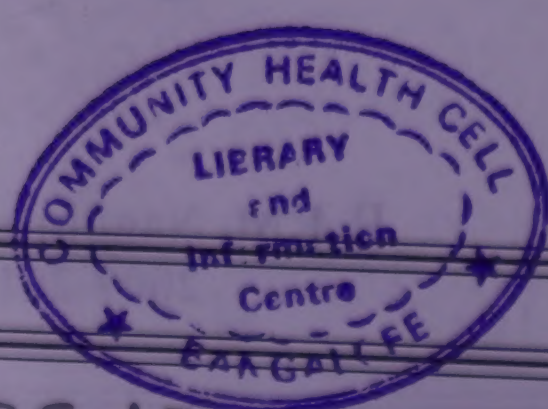
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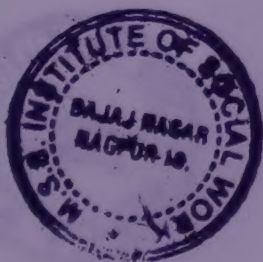
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This research has been submitted in partial fulfillment of the requirement for the Masters in Philosophy in R. T. M. Nagpur University, it is forwarded to the R.T.M. Nagpur University.

Date:- 10/10/2010

Place:- Nagpur



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(Dr. John Menachery)

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This work of research is comprehensive, complete and sufficient to the standard of academic requirements. She has submitted this dissertation in partial fulfillment for Master in Philosophy in Social Work from R.T.M Nagpur University.

It is here by forwarded to RTM Nagpur University for examination.

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Declaration

7

I, the undersigned, solemnly declare that the dissertation entitled “A Study of Psycho-Social Barriers of low Adherence in HIV Therapy and social work intervention with special reference to ART centre, Indira Gandhi Government Medical College , Nagpur.” is my original work carried out under the supervision of Ms. R. Babhulkar , Matru seva sangh, Institute of social work , Nagpur.

This dissertation is not substantially the same as Any other study or research work. This work or any other resembling this has not been submitted to any other examination of this University or any other University .




(MS. Varsha V. Bhagat)
Researcher

Acknowledgement

First I thank God for giving me strength during my study. I sincerely thank my Principal Dr John Menachery, my guide Ms R. Babhulkar for providing and guiding me with their vast and profound knowledge for the completion of this research study.

I am very much thankful to Dr Mrs. S.G. Gaikwad in supporting me for the research study and also providing with the assistance of her knowledge of compilation of the data collected.

I am indeed grateful to the staff of the ART centre of the IGGMC college, especially Dr. Girish Ambade Sr. Medical Officer ART centre for providing his valuable knowledge with respondents and also giving me the permission to carry out the data collection for the research study without which it would not have materialized to complete the research.

I am thankful to my family for all the adjustments they made to help me carry out my research study, particularly to my husband Mr H. G. Gaikwad for supporting me financially and morally during my studies and entire period of my research.

Last but not least I wish to convey my thanks to all my friends who helped me in one way or another, directly or indirectly contributed in their way for successful completion of the research study.

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"AIDS does not inevitably lead to death ... It is very important to tell this to people. Psychological factors are critical in supporting immune function. If you suppress this psychological support by telling someone he is condemned to die, your words alone will have condemned him."

- Luc Dr. Montagnier,
Discoverer of HIV

Chapter - I

A. INTRODUCTION

**A Study of Psycho-Social Barriers of low Adherence in HIV Therapy
and social work intervention with reference to ART centre,
Indira Gandhi Government Medical College, Nagpur.”**

Chapter I

A- Introduction

June 2010 marks 26 years of AIDS. On June 5, 1981, the USA based Centers for Disease Control and Prevention (CDC) first published report on a rare kind of pneumonia in five gay men, and that report is taken to mark the “discovery” of AIDS (Acquired Immune Deficiency Syndrome). At first, the syndrome was called Gay –Related Immune Deficiency (GRID) or gay cancer. The term AIDS was coined by the CDC in 1982.

Within three years, in 1984 researchers isolated HIV (human immunodeficiency virus), the virus that leads to AIDS. This identification of the virus is credited to Luc Montagnier of the Pasteur Institute in France and Robert Gallo of the National Institutes of health in USA.

AIDS is now second only to the Black Death as the largest epidemic in history. AIDS kills about 2.9 million people a year or about one person every 11 seconds. The death toll surprisingly includes a lot of children, who are often infected with HIV virus during pregnancy or through breast feeding. Other reasons could HIV can be transmitted from an infected person to another through Blood (including menstrual blood), Semen ,Vaginal secretions, and Breast milk However the "bodily fluids" like Saliva, Tears , Sweat , Urine, and feces are not infectious.

In May 1986, the International Committee on the Taxonomy of Viruses ruled out all other previous nomenclatures and named it as HIV (Human Immunodeficiency Virus). There are two similar HIV viruses, HIV-1 and HIV-2. Both cause clinically indistinguishable AIDS. HIV-2 is less virulent and less infectious than HIV-1. HIV-1 is found throughout the world.⁷ Both HIV-1 and HIV-2 are found in India, but the vast majority of infections here are of the HIV-1, sub type C.

When a person is infected by HIV, there is burst of activity as the virus multiplies and the immune system attempts to battle it by producing antibodies. During this period, the viral load (The number of virus particles the body is carrying) is high and the infected person is highly infectious. But a person's HIV status cannot be detected at this stage using standard tests because sufficient antibodies have yet to be formed. This is commonly called 'WINDOW PERIOD' and lasts from several weeks to about three months. An infected person will usually experience an episode of illness at the end of window period. The symptoms could include lack of energy, fever and night sweats and diarrhea over period of more than a month.

The reasons and diagnosis of HIV/AIDS are not discussed here for want of space so also it is not required. The concern here is the low adherence among the HIV/ AIDS infected individuals whose number is galloping high which could be 10 million people worldwide (Mahler, 1986, Internet information).

Researches are on an increase in different spheres of the disease – awareness, medicines, effects and side effects of the medicines, the causes being well defined. A huge number of people are affected with HIV and the number is fast increasing. The treatment is still not within the reach of the down trodden. The middle class too has to struggle hard to purchase the medicines though the cost is claimed to be reduced. **Even though the anti HIV drugs are available the occurrences of the side effects plays a large role in adherence to drug regimens, which in turn can impact the development of drug resistance (Bulletin of Experimental Treatments for AIDS April- 1998 issue.)**

Being HIV positive means, one now carries the virus that causes AIDS. It does not mean that one has AIDS, nor does it mean that one will die. Although there is no cure for AIDS, many opportunistic infections that make people sick can be controlled, prevented or eliminated. This has substantially increased the longevity and quality of life for people living with AIDS. Yet there are things that one can do to stay healthy. Emotional support may be very important for HIV-positive people because it breaks the isolation and provides a safe way of sharing both feelings and practical information. It is important for people who are HIV positive to seek regular care from a physician. Such care will provide them with important information about the progression of their disease and will assist them in deciding whether to start taking antiretroviral medications. The first step in getting care for HIV/AIDS is to choose a physician. Obviously, it is best to find a doctor who is familiar with treating HIV disease. Doctors who don't specialize in HIV treatment are not likely to keep up with rapidly changing developments in drug therapies and treatment strategies.

Once a doctor or clinic is identified, the main objective is to get an evaluation of general health and immune function. The doctors evaluate the immune system to determine if one has other diseases that might become problematic in the future, including syphilis, TB, hepatitis-B, and toxoplasmosis. If one is already infected with one or more of these other illnesses, there may be treatments or prophylaxis available to prevent it from becoming more serious or recurring in the future.

The discovery and understanding of viral reservoirs have diminished the rationale and enthusiasm for early treatment. The consensus today is that by using the currently available medications, it's impossible to completely eradicate the virus. However, present HAART (highly active anti-retroviral therapy) may prevent viral resistance and permit long-term control. Toxic side effects may preclude a person's ability to tolerate these medications over the long term. It's almost impossible for an individual to properly adhere to the drug-taking regimen in order to prevent resistance from forming. Also recent studies have shown that individuals who defer therapy until their CD4 counts fall to 200-350 do as well as those who start therapy earlier.

There are several thought about the Antiretroviral Treatment (ART) in the Context. Recent changes in global funding, international health policy and the availability of antiretroviral treatment (ART) have created new hope in the face of this daunting epidemic. With widespread access to antiretroviral drugs priced at \$150 per year, the 15th International AIDS Conference's agenda of "Access for All" is both a feasible and a reasonable goal. In 2003, the WHO and its partners in the Joint United Nations Program introduced a bold, new plan to expand access to HIV therapy in the developing world and, ultimately, provide universal access to ART by 2010. Dubbed "3 by 5", the target was to provide ART to 3 million people in low- and middle-income countries by the end of 2005.z

In 2005 1.3 million people received HIV antiretroviral treatment in low-and middle-income countries; WHO estimates that this expanded access to ART averted an estimated 250,000 to 350,000 premature AIDS-related deaths. Although access to ART and care has improved drastically over the past few years, the AIDS epidemic still claimed 3.1 million lives in 2005 .The still considerable AIDS death toll highlights the disparity between the ART roll-out's potential and its reality in the developing world.

Antiretroviral therapy does not work the same for everyone, however, and there is still some debate about when is the best time to begin. Choosing the right drug combination can be a challenge, even for clinicians. Antiretroviral drugs (especially protease inhibitors) are also associated with side effects that may increase the risk of other illnesses, such as heart disease. Despite the development of generic versions of anti-HIV drugs--treatment remains out of reach for some 90% of people with HIV/AIDS worldwide.(*Draft Strategic Framework for the Human Resources for Health Plan of August 2005*)

The goal of antiretroviral therapy is to prevent HIV from replicating (making more copies of itself). The antiretroviral drugs that are currently available belong to four classes: nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), and entry inhibitors.

Each class of antiretroviral drugs fights HIV in a unique way. NRTIs (such as AZT and tenofovir) and NNRTIs (including Sustiva and nevirapine) interfere, in different ways, with the production of reverse transcriptase, a protein the virus must use in order to replicate. PIs (such as Kaletra and saquinavir) interfere with HIV's use of the protease enzyme, another component essential to its replication. Finally, the entry inhibitor Fuzeon prevents HIV from entering cells and making more copies of the virus.

Like any medication, AIDS treatments may cause side effects. Many side effects depend on the patients past use of HIV medications. Often side effects-such as, Anemia , neuropathy (pain, tingling, loss of feeling in the hands and feet), nausea, diarrhea, dizziness, and nightmares-can be minimized or eliminated by switching medicines, or switching the time of day they are taken, or adding other medications to counteract the side effects. Some of the side effects are Gastrointestinal side effects, Hepatotoxicity, Renal problems, Neurological side effects, CNS disorders

A community out-patient experience states:

Patients' knowledge of their HIV condition and its treatment has been recognized as a factor that influences adherence to antiretroviral therapy. Patients' knowledge & perception of the disease and participation in the treatment can be improved through targeted educational programs and support groups. One study done in Nigeria found that individuals living with HIV/AIDS who belonged to a support group and had availed themselves of relevant literature were more knowledgeable and positive about their illness than those who did not belong to support groups. The study concluded that HIV/AIDS support group membership is an important component of psycho-social care in HIV/AIDS patients . Another study done in France showed that an educational intervention improves adherence to antiretroviral regimens and health status and suggests that it should be initiated early in therapy . Communicating with patients about adherence issues is important issue, although this may not have an immediate impact on patients' behaviors. Health care professionals should play a pro-active role in this regard. The use of multi-disciplinary adherence teams to ensure that each HIV-positive patient receives the optimal amount of information and support for adherence is a practical approach.

Health literacy should be provided in the context of different ethnicity, culturally sensitivity and individual needs associated with HIV, like any other chronic diseases. Therefore, special care should be taken by health care providers to ensure treatment compliance and health literacy in these patients. Psychological impact associated with treatment of any chronic illness is often neglected in clinical practice but indeed carries a huge significance in terms of long-term treatment compliance and outcome. Seven of their patients who clearly expressed psychological issues related to their HIV infection and it was evident enough that those psychological problems were adversely affecting their treatment compliance. Formal and regular counseling sessions should be arranged for HIV/AIDS patients to promptly identify and manage any psychological or psychiatric disturbance that HIV patients might suffer from. We know that presence of a preexisting psychiatric disorder can increase the risk of HIV acquisition and can also complicate HIV treatment. Successful treatment can be achieved with even the most difficult patients by applying a comprehensive diagnostic formulation that includes psychiatric disease syndromes such as major depression, personality vulnerabilities, behavioral disorders such as addiction, and problems of life experiences such as trauma, with regards to anti-retroviral treatment of HIV positive or AIDS patients.

The conclusions drawn were :

By identifying the demographic, socio-economic, behavioral and psychological variables which significantly influence patients' adherence to treatment and understanding of the disease process, they stated that they can further improve treatment compliance and the long term prognosis of our HIV patients. These factors may not have very significant role individually, but collectively can dictate the course of success of HAART treatment in patients. Increasing awareness of these factors by practitioners caring for HIV-infected persons, recognizing and potentially treating some of them, should indirectly improve the effectiveness of antiretroviral therapy.

Demographic characteristics

Although it has been well demonstrated that certain demographic and HIV risk groups have poorer access to therapy [e.g., African-Americans and injecting drug users (IDU)]

few data are available on the influence of these factors on adherence among HIV infected patients. Demographic characteristics have been associated with decreased adherence in a variety of disorders, including chronic illness, mental illness, and amongst the elderly.

Age

Adherence increases with age, except in the most elderly (those aged over 75 years) [21]. Often, the very elderly have more complex medical regimens and more co morbidities, such as vision, hearing, or memory impairment. In comparison, studies of medication adherence in patients aged under 75 years with chronic or mental illness showed a positive correlation between age and adherence. In one prospective evaluation of patients with HIV that addressed this issue, age did not correlate with adherence. However, HIV-infected individuals are typically no older than 50 years. Thus, risks associated with old age may not be a major issue.

Gender

In several studies of patients with HIV infection, chronic illness, mental illness, and the elderly, male gender was associated with decreased adherence. However, other studies have not found a significant association between men and decreased adherence. Notably, in one study of HIV-infected patients, it was observed that women were missing a higher percentage of clinic visits than men. As a result, free on-site child care was provided, and adherence with scheduled visits improved dramatically. In situations where women are responsible for care of the household and children, immediate concerns or practical barriers may adversely affect adherence among women more than among men. As rates of HIV infection are increasing among women, the extent to which these barriers can be alleviated may have a significant impact on treatment outcome.

Socioeconomic status

Lower socioeconomic status (SES) has been shown to be another contributor to decreased adherence. The components of lower SES associated with decreased adherence are unstable or poor housing, low income, low level of education and lack of medical insurance the latter factor particularly important in the United States. Low income and lack of insurance may prevent patients from easily accessing health care, in terms of purchasing medications, transportation, or child care. Poor housing may either contribute

directly to lower adherence by preoccupying the patient with more immediate concerns, or be an indirect indicator of low social support and educational status. These risk factors may also apply to IDU. In a cohort study of HIV-infected IDU, unstable or poor housing, low income, and lack of insurance were associated with lower adherence to zidovudine treatment. One study found that low adherence in urban indigent patients with HIV was associated with limited health resources and access to health assistance until significant immune suppression occurred. Medical assistance and other public sector programs may need to provide resources earlier in the disease course to maximize compliance.

Psychiatric/psychological stress

Presence of psychiatric illness is commonly associated with decreased adherence in patients with mental illness, elderly status, and HIV infection. Other psychological factors associated with lower adherence among the mentally ill are hostility, guilt, anxiety, paranoia, and grandiosity. In a prospective study of HIV-infected individuals, compliant patients (defined as $\geq 80\%$ adherence) had significantly less depression than non-compliant patients. In a large study of zidovudine compliance, only 52.6% of patients diagnosed with psychiatric illness had good compliance, compared with 81% compliance in those without psychiatric diagnosis. (Bose 2009)

Adherence with HIV therapy

Depression is the most commonly cited psychiatric problem among HIV-infected individuals, with prevalence rates ranging from 17 to 30%. It has been suggested that active psychiatric intervention should be an important component in the effective management of HIV-infected patients.

Patient attitudes and beliefs

Negative attitudes about medications or illness may also interfere with patient adherence. Amongst the mentally ill, reasons cited for not taking medications were fear of addiction and the belief that medication use was a sign of weakness. The patient's perception of how beneficial treatment would be in affecting illness outcome was also associated with compliance. Amongst HIV infected patients, attitudes and beliefs related to decreased adherence included the patient's acceptance/ perception of disease, and perceived lack of benefit. Specifically, scepticism about zidovudine (perceived lack of benefit) and denial

of necessity of treatment have been associated with decreased adherence . Conversely, the belief that zidovudine prolongs life has been strongly associated with increased adherence. Perceived lack of benefit and lack of necessity for treatment can also be risk factors among patients with chronic illness.

Social relationships/activities

Poor social relationships and activities have been associated with lower adherence in several studies. In the mentally ill, lack of involvement by family and friends, social isolation, and living alone, were found to be risk factors. In comparison, a broader array of social activities had a positive effect on adherence. Living alone and lack of support have also been associated with increased risk of non-adherence in the elderly. Kissinger *et al.* speculated that HIV infection is a potential cause of social isolation. Thus, social isolation may be a risk factor for decreased compliance in HIV infected individuals. However, in one study, higher perceived social support was not found to be significantly associated with adherence.

Medication characteristics Form of medication

In their review of adherence in ambulatory patients with schizophrenia, Young *et al.* [10] presented data summarizing the observed ranges of default rates with oral medications in 28 studies. Default rates for oral medications ranged from 10 to 76%; injected medication default rates ranged from 14 to 36%, but in general were considerably lower than rates for oral medication. Due to the simplifying nature of the form of the medication, the depot form of medication seems to have a higher rate of adherence. A higher rate of adherence to depot medication has also been shown by comparing use of oral contraceptives with levonorgestrel implants (a sustained-release contraceptive that is implanted subcutaneously) . In addition to reducing dosing frequency, depot preparations are also more likely to be supervised. Like depot injections, oral controlled-release drugs, such as procainamide for cardiovascular use, can decrease side-effects and prolong dosing intervals, increasing patient compliance. Using drugs with longer half-lives can also reduce dosing and prolong dosing intervals. Although depot forms are not likely to be an option in HIV disease, combined pill forms, longer half-life drugs (e.g., single daily dose), or long-acting controlled-release forms may become important strategies in improving compliance with antiretroviral therapy.

Side-effects

Amongst the mentally ill, specific side-effects are associated with decreased adherence]. In schizophrenic patients, an initial dysphoric response to thiothixene, or extrapyramidal side-effects related to fluphenazine decanoate have been associated with medication cessation or reduced dosage. In a small subset of mentally ill patients, discontinuance of medication occurred as a result of fear of side-effects . Undesirable side-effects were also a risk factor for non-adherence in chronically ill and elderly patients, such as insulin cessation in diabetic patients. In patients with HIV infection, major side-effects leading to decreased adherence and treatment cessation are leukopenia, anemia, transfusion, and gastrointestinal upset and one reason for refusal of zidovudine is fear of side-effects]. It is possible that combination antiretroviral regimens will result in a greater risk of adverse effects. Given that the prognosis of AIDS is so poor in untreated patients, patients with HIV may tolerate side-effects better than patients with less severe chronic diseases such as hypertension or diabetes.

Complexity of prescribed regimen

As the complexity of the prescribed regimen increases, so do rates of non-adherence. Moreover, as a prescribed regimen becomes more complex, it also becomes more inconvenient and difficult to incorporate into daily living. A medication timer may be one possible solution, and has been shown to increase compliance in a study of HIV-infected patients . Nevertheless, in patients who are less motivated, who have less social reinforcement, or who live disordered lives (e.g., IDU, alcoholics), regimen complexity may prove to be an insurmountable barrier.

Health-care administration and delivery Patient knowledge

Patient non-adherence has been found to be significantly associated with the patient not knowing the correct dose of medication or that chronic medications have to be taken continuously. In a sample of elderly adults, 50% of the non-adherent group reported skipping a prescribed drug because they did not believe they needed it . A group of non-adherent mentally ill patients claimed remission of symptoms as a reason for medication cessation . Although this may not be of concern for patients with chronic or acute illness and physical symptoms, a study of coronary artery disease in the elderly has suggested

that patients may be more adherent to medications that relieve their symptoms (i.e., they may be more likely to take their anti hypertensives than their prophylactic aspirin). Conversely, instead of stopping medications because they are feeling better, some patients abandon their medications due to delay of clinical response, or failure to provide a 'cure' within a limited period . If these results extend to patients with HIV infection, it becomes important to explain to patients the necessity of continued medication during symptomatic periods. In the absence of symptom cues, informing patients of their HIV viral load and CD4 count during chronic antiretroviral therapy may assist adherence. Patients' lack of knowledge of their diagnosis and the expected course of their illness or treatment has also been associated with decreased adherence. One study found that patients who learned the names of their medications were more adherent than those who did not know the medication names .

Health-care practitioner–patient communication

Patient education as to the correct use of medications relies primarily on health-care providers. Even when patients have received proper instruction, it may be difficult to remember to take medications as prescribed. In these situations, the practitioner can work with the patient to incorporate the individual drug regimen into a daily schedule. Several strategies have been suggested: timed pill dispensers, alarm clocks, and having someone else to act as a reminder. In patients with mental illness, specifically targeted education about illness treatment and medications has improved adherence . In a study of hypertensive patients, adherence increased proportionally with the number of times the patient talked to a doctor about hypertension . Lack of a primary care physician also carried an increased risk of decreased adherence . (Mehta et al. 1997)

Over the past decades there have been different approaches which were aimed at ensuring that client continue with therapy for chronic condition for prolonged period of time . the first of such approach was lying emphasis on role and responsibility of client and more recently role of health care providers have been included health care provider and client together ensure that client should be obtain optimum health and maintain it over years through sensible adherence to treatment .

Who defines adherences as the extent to which persons behaviours , taking of medication and the following of a life style including a healthy diet and other activites corresponds with agreed recommendations of the health care providers .

Role of Social Worker as Counselor in ART centre play a very important role in helping clients to their treatment by helping them to identify possible challenges and solutions to managing treatment as successfully as possible and Maintaining quality of life .Counseling aims to improve clients knowledge about the disease ,the medication and its side effects, set treatment goals and plan to set positive .belief and perception.

Adherence counseling is to be started at the preparation stages for ART itself and adherence needs to be monitored and reinforced during the treatment phase.

The objectives of adherence counseling are the following.

1. Help the clients develop an understanding of their treatment and its challenges
2. prepare the client to initiate treatment.
3. Provide ongoing support for clients to adhere to treatment over long term .
4. Help client develop good treatment taking behavior.
5. Help the client in setting goals for their treatment .

Chapter-I

B. RESEARCH METHODOLOGY

B - Research methodology

Before the researcher gives the methodology she feels it appropriate to give a brief account of what research is and how it helps the researcher.

Research is a means of increasing the scope of knowledge understanding the problem and finding a solution, and ultimately making human life progressive and flourishing. The thought process which helps to achieve or create new knowledge can be called 'research'. It can be said so because this thought process is scientific in nature and is used to resolve the problems. Research not only helps in creating new knowledge but also develops new perspectives regarding the knowledge that exists, and further develops knowledge based in this perspective. Thus it is a cyclic process. It helps to analyze the events/ situation and establish new relationship, improve the measuring tools or create new more effective tools of measurement and create a healthy situation for the development of mankind in the global prospective.

A good research process consists of the following steps:-

- Selection of area and a topic for research.
- Understanding the literature related to the topic.
- Statement of the problem, hypothesis and assumption.
- Analysis and definition of the concepts in the problem stated.
- Collection of the data/ information. Analysis of the data collected and so on.

The researcher has conducted an experiment. The objectives of the study, the hypothesis, etc are as follows the methodology is as follows:-

Selection of the Topic:

Under NACP (National AIDS Control Policy)-II, focus was given on low cost care, support and treatment. Anti Retroviral Therapy programme was launched in the year 2004. On 31st August 2008, a total of 179 ART centre's are functional ,giving free Anti Retroviral Therapy at these centres. Function of ART centre can be categorised in medical, psychological and social field. Advent of antiretroviral treatment began transforming HIV from a killer disease to manageable choronic illness. ART suppresses

viral replication and can halt disease progression-ART does not cure HIV infection or AIDS.

All HIV positive clients need to be clinically examined before starting the ART to establish the need and eligibility for ART. Criterion for starting ART is based on a positive HIV test and either medical symptoms categorized by the WHO in 4 clinical stages.

Clients whose CD4 counts fall below 250 should start therapy, CD4 cells are important in the body's immune response to fight off the infection, low CD4 count indicates the need to start the treatment, but it is yet to be determined what the exact count should be at initiation.

Since the advent of highly active antiretroviral therapy, or HAART, many HIV positive people now live longer with HIV and have a better quality of life and health. New drugs and new formulations continue to simplify anti-HIV therapy, allowing many HIV positive people to take only a few pills a day.

The goal of antiretroviral therapy is to prevent HIV from replicating (making more copies of itself). The antiretroviral drugs that are currently available belong to four classes: nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), and entry inhibitors.

Each class of antiretroviral drugs fights HIV in a unique way. NRTIs (such as AZT and tenofovir) and NNRTIs (including Sustiva and nevirapine) interfere, in different ways, with the production of reverse transcriptase, a protein the virus must use in order to replicate. PIs (such as Kaletra and saquinavir) interfere with HIV's use of the protease enzyme, another component essential to its replication. Finally, the entry inhibitor Fuzeon prevents HIV from entering cells and making more copies of the virus.

In the past one and half decades, lessons learnt have indicated increasingly central role of adherence to the success of ART. Both patient and health care providers face significant challenges with respect to adherence to ART. Once initiated, These medication have side effects, some of which may temporary while others may be more permanent have requiring change in treatment. Inadequate adherence to treatment is

associated with detectable viral loads, development of viral resistance , treatment failure declining CD4 counts , disease progression , episodes of opportunistic infection and poor health outcomes. The consequences of low adherences are serious for individual, for public health.

Nagpur district is ranked second highest in prevalence of HIV in Maharashtra after Mumbai. According to the UNAIDS 2006 report which states, that affect Nagpur area of Maharashtra state is specially effected. There are around 3000 People living with HIV are registered at ART Centre, Indira Gandhi Government Medical college, Nagpur . Client which are taking HIV therapy are 1800 registered. According to the latest reports it seems that there has been an rise in the number of missing clients and having adherence lower than 80% who are undergoing treatment..

Low Adherence means client not taking a medicine as prescribed by the doctor, which includes taking prophylactic medicines for the opportunistic infections (OIs) along with ART. Taking medicines the right way is very important for the treatment success. If a client misses or takes reduced doses or stops taking the medicine. HIV can learn to survive despite the medicine. This may cause the infection to change or get stronger, and the current prescribed medicines may no longer work. This could lead to drug resistance or treatment failure.

Researcher is working as a counsellor at the ART center. The researcher here wants to make a point in identifying the psychological and social barriers of low adherence to the ART. Psychological barriers like depression/stress, Fear of Side effects of ART, Recurrence of Opportunistic infection, pill burden ,Differences with spouse or family member, Loss of /partner and living alone, Addiction of Alcohol and substance, Change in daily routine life style. Social barriers like Social stigma ,fear of disclosure HIV status, Religious belief , blind superstitious ,limited faith in the treatement .Lack of family and social support,, Financial constraints/travel costs /lower economical status,. Migration and frequent traveling for employment

Review of literature

As far as any scientific and systemic research is concerned , review of literature is very important aspect . the researcher had gone through a number of lit material what to related HIV/AIDS . existing literature help to the re to have better understanding sand deep knowledge of subject . the review of existing lit also helped there to formulate the question are in the best way possible .

Objectives of the study:

1. To study the personal and family background of respondent .
2. To study psychological problems of the respondent which leads to low adherence.
3. To study social problems faced by respondent due to HIV infection which leads to low adherence.
4. To study information related to effect of the ART treatment which respondent have .
5. To suggest suitable measures for reduction psycho-social barriers regarding treatment .
- 6.

Hypothesis:-

“A Hypothesis is a shrewd guess or inference that is formulated and provisionally adopted to explain observed facts or conditions and guide in further investigation. The wording of the hypothesis will determine the particular line along which the experiment is to develop.”

Formulation of hypothesis gives a definite point to the enquiry, aids in establishing the direction in which to proceed, and helps to delimit the filed of enquiry by singling out the pertinent facts on which to concentrate and by determining which facts should said aside, at least for the time being. The use of hypothesis thus prevents a blind search and discriminate the gathering of data which may later prove irrelevant to the problem under the study. Without it research is unfocused random empirical wandering.

The hypotheses framed for the study are as follows:

1. Duration of treatment and psychological barriers are interdependent among the 'On ART' clients which lead for low adherence to HIV therapy.
2. Duration of treatment and sociological barriers are interdependent which resulting into low adherence. 7
3. Lack of Networking with NGO s leads low adhere
4. Lack of Knowledge about HIV/AIDS among the respondent leads to low adherence.
5. Unaware about importance of adherence of ART leads to low adherence.

Operational Definitions:

On ART clients: On ART clients here means the respondents who are undergoing the HIV therapy

Age : this refers to the number of years that an individual has lived since date of birth.

AIDS : this refers to a progressive immune deficiency caused by infection of CD4+ T cells with the human immunodeficiency virus (HIV).

CD4+ : this refers to an antigen maker of helper/inducer T cell that recognizes antigens bound in class II MHC protein.

Discrimination: is described as the act of making a difference in treatment, favoring or punishing on the basis other than individual merit.

Stigma : is defined as something that brands a person with a negative description, marks of disgrace or shame. Stigma can take the form of feelings or thoughts, conscious or subconscious.

Prevalence : this refers to the number of affected persons present in the population at a specific time divided by the number of person in the population at that time.

Study of Psychological problems : The barriers that are related to the psychology of the individuals undergoing HIV therapy are considered

Social barriers: The barriers that are related to the social aspects of the individuals undergoing HIV therapy are the social barriers

Adherence: ability to follow a treatment plan , take medications at prescribed times and frequencies and follow restrictions regarding food and medication.

Low adherence or less than 80% in HIV Therapy: client not following systematic intake of the medication and directions by the Health Care Providers. Client have taken fewer pills than required .

HIV therapy: Anti retroviral therapy is life long treatment that consist of multiple medications to be taken two to three times a day with varying dietary instruction.

Research design:

Research Design refers to the perfect planning of even the minute aspects of the research procedure. Selitiz and others define research design as arrangement of the conditions for collection and analysis of data in a manner that aims to combine relevance to the research purpose with economy in procedure. Research design indicates the entire process of planning and carrying out a research study prior to the actual field work so that the researcher would go ahead with investigation clear ideas of selling and other steps concerning the research work. Each type of research required a particular type of design. Type of research is based on the purpose of research and the nature of the problem chosen for research. Therefore, the research design also depends upon the nature and dimensions of the whole process of research.

Four different type of designs are available for social investigator. the researcher had to choose one among them that will suit this research problem to be analysed.

The function of a research design is to ensure that the required data are collected and that they are collected accurately and economically. it is a plan that specifies and objective of the study and the hypothesis to be tested and is a blueprint for the method to be adopted for gathering and analysis data. In this study researcher has used diagnostic design to study the social and psychological problem of PLHIV Diagnostic study at discovering or analyzing some specific problem and focused towards some possible solutions. A diagnostic design basis itself on the knowledge which can be put into practice in the solution of the problem .It is design which deals with problem as well as solution.

The major variable of the study

1. Personal information
2. Social information
3. Psychological information
4. Information of awareness and prevention
5. Information on social work intervention

The interview schedule and questionnaire was prepared on the basis of the above major of the variable of the study

Area of Study

Client who are registered in ART Centre at the Indira Gandhi Government Medical college in Nagpur who are undergoing HIV therapy but having adherence lower than 80%.

Scope of study:

The study can be applied to a larger population. It can be extended even to the whole of population (world). The researcher will identify the possible solutions for challenges posed by the barriers in adherence in the HIV therapy which will be help full to the fellow counselors in the future

This dissertation directs towards expanding future HIV/AIDS adherence research by inclusion of social and structural determinants of health in assessment of utilization and ability to sustain care beyond the individual level.

Method of Data Collection

Sampling method ;

Researcher got monthly list of missing and low adherence client registered from March 2008 to December 2009 in Indira Gandhi Government Medical College ART centre .

In this study, researcher has used the probability sampling with sequential method.

Sample Size:

Total 110 respondents whose adherence is less than 80% .Out of 110 only 90 responded and hence the data processed is of 90 respondents only.

Tools/Instruments of Data Collection:**A. Primary Method**

Interview Schedule; Reaseacher has been collected data by using method of Interviewing .Researcher made a Interview schedule with both open and closed ended question.

A questionnaire has develop for data collection regarding information

B. Secondary Data

These are the information which is attained, which is generally from published or unpublished material. In collecting these secondary data, books, journals, Internet, Literature from MSACS, NACO and periodicals which are related to this subject are used.

Data processing ,

Included classification , editing coding, reparation of Master chart and tabulation

Once the data has been collected it has been processed. This processing work includes:

- A. Coding :** Answers of all questions including the open ended questions been coded with help of code book.
- B. Master chart:** The coded responses, as per code book of each respondent were carefully transferred into the Master chart
- C. Tabulation:** Simple and cross tables has been made according to objective and hypothesis with help of master chart.
- D. Analysis and interpretation of the Data:** The data thus tabulated and it is used for Analysis and interpretation of the study and conclusion has been drawn.
- E. Conclusion and suggestions:** After the analysis and interpretation next step is to be make Conclusion and suggestions

Chapterisation :

Chapter I

- A) Introduction
- B) Research Methodology

Chapter II -

Data Analysis and interpretation

Chapter- III

- A. Major findings
- B. Conclusions
- C. Suggestions

Appendix – A. Interview schedule

B- Bibliography

Annexure

Difficulties and limitations in the study:

Contacting the missing and low adherence on ART clients as a very difficult job. ART centre provided list including address, but some client had given wrong address, Researcher visited their homes to take the follow up through casual talks. Researcher had faced great difficulty in the beginning due to stigma, clients may be hesitant to speak up and give information. Using lot of motivational force and taken into confidentiality through perseverance after the consent they were gradually opened up.

Chapter-II

DATA ANALYSIS, TABULATION & INTERPRETATION

Age:-

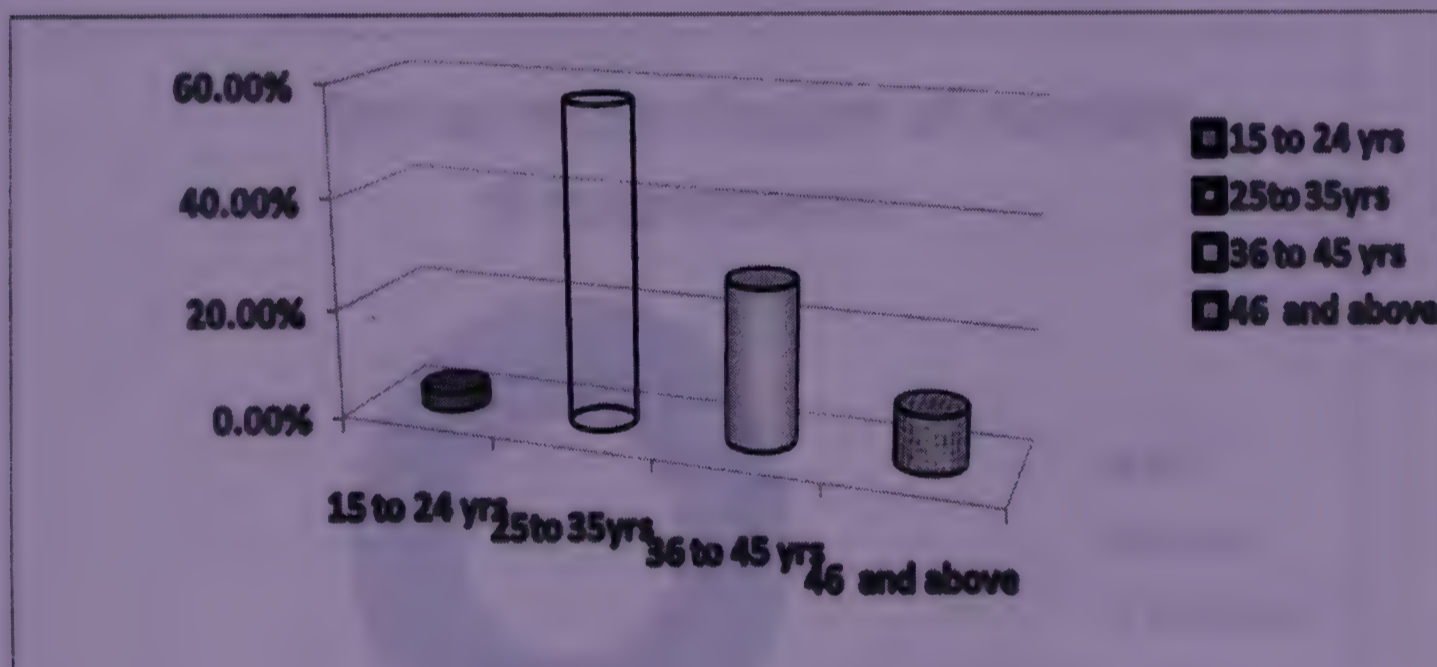
Every individual undergoes different stages of age in lifetime. Every age has its own peculiarities and impact. Maturity totally depends upon the age. Researcher wants to find out correlation between age and adherence.

Table 2.1
Age wise distribution of respondents.

Sr no	Age group	No of respondents	Percentages
1	15 to 24 yrs	03	3.33
2	25to 35yrs	52	57.77
3	36 to 45 yrs	26	28.88
4	46 and above	09	10
	Total	90	100

Following cylinder shape figure showing Age wise distribution of respondents.

Figure no .2.1



The above table shows that 03 (3.33%) respondents belonging to 15 to 24 years age group and there are 52 (57.77%) individuals belonging to age group of 25 to 35 years. The respondents in the age group of 36 to 45 years are 26 (28.88%) and 9 (10%) are of age above 46.

The 57.77% respondent belonging to 25 to 35 years is the highest group having low adherence.

Gender:-

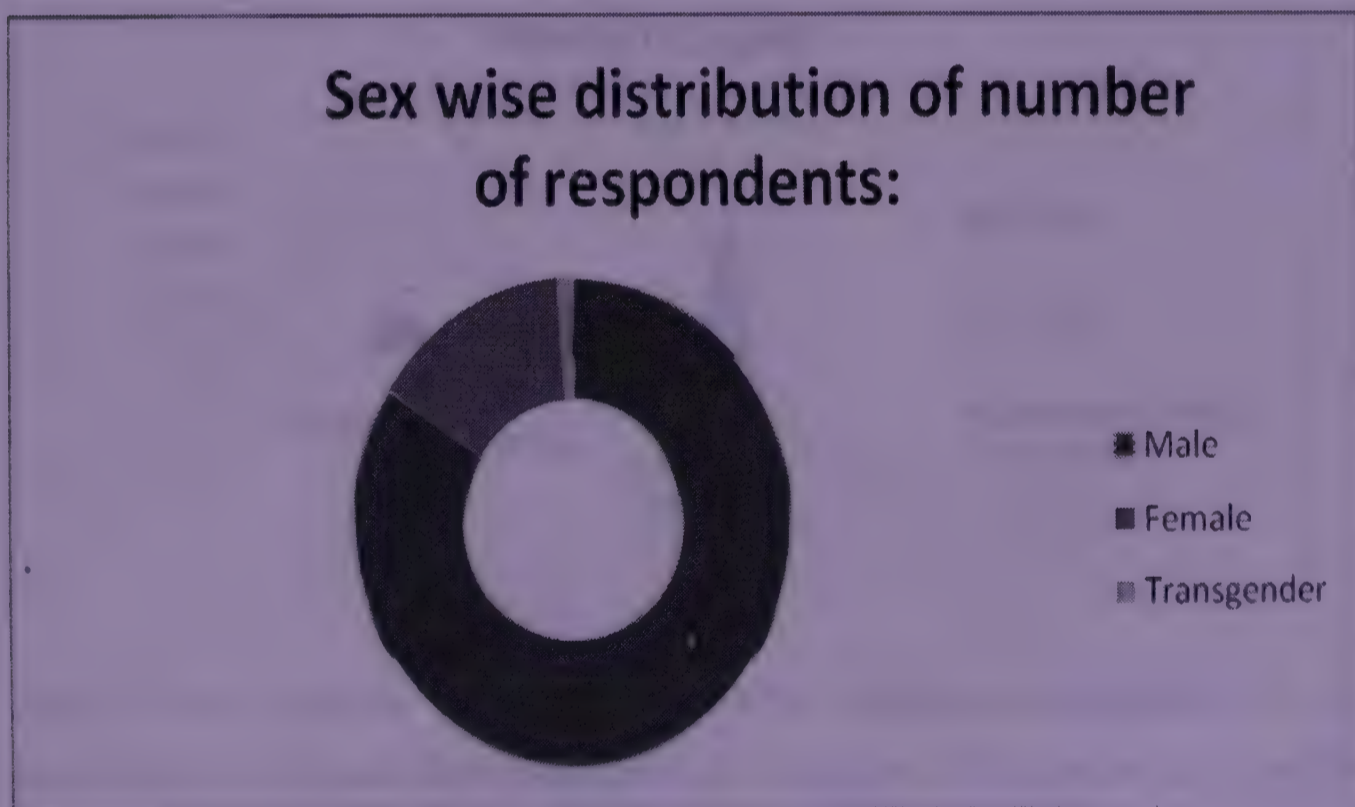
Gender is a determinant factor for all discrimination and stigma which are available in the society. Gender also speaks about strengths, weaknesses, superiority and suppression. Researcher wants to know how the Gender is associated with treatment adherence.

Table 2.2
Sex wise distribution of number of respondents:

Sr no	Sex	No of respondents	Percentages
1	Male	75	83.33
2	Female	14	14.55
3	Transgender	01	1.1
	Total	90	100

The following distribution of the respondent on the basis of gender has been shown in the doughnut shape figure.

Figure no 2.2



It is obvious that total number of male individuals are high in number i.e. respondent are 75(83.33%) and female respondent are 14 (14.55%)and Transgender is 1(1.1%). The table shows that 83.33% male respondents are having highest low adherence .

Educational status:-

Education has become an essential commodity today. It plays an important role in an individuals life and helps in the development of a person. It also helps in improving the status as well as self image so also to study the adherence to treatment.

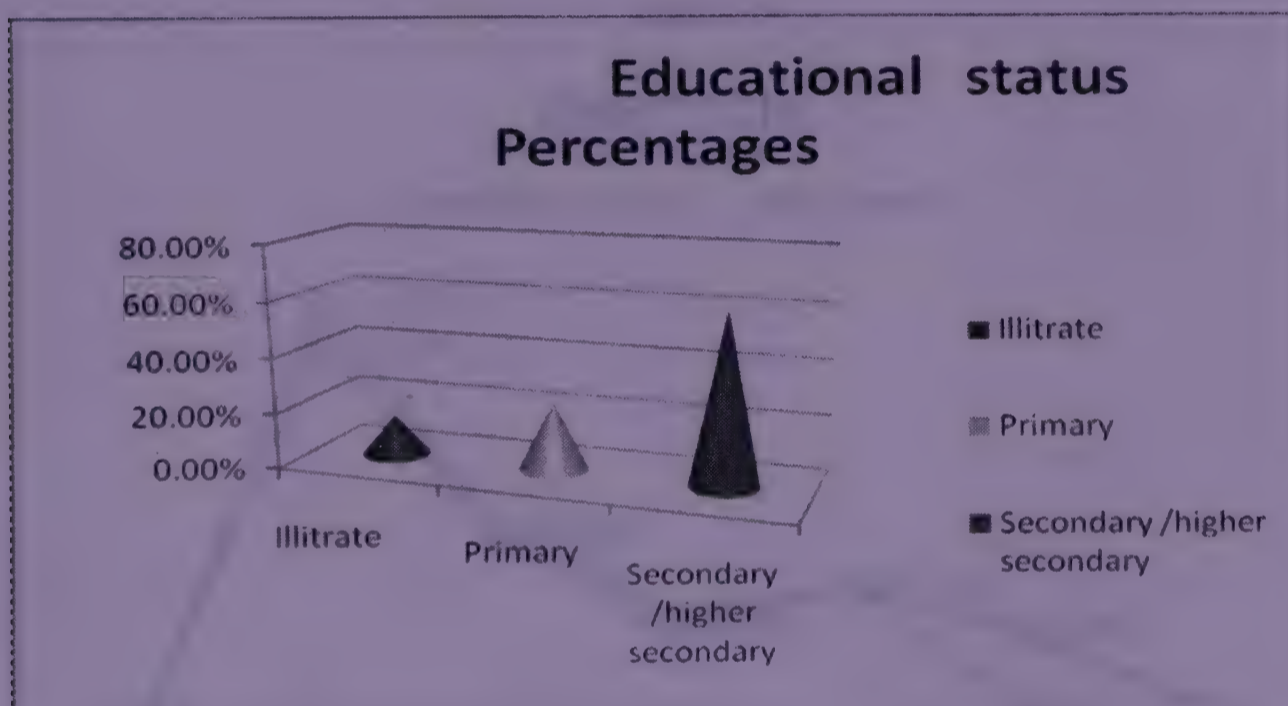
Table no 2.3

Educational status of respondents

Sr.no	Education	No of respondents	Percentages
1	Illiterates	13	14.44
2	Primary	22	24.44
3	Secondary /higher secondary	55	61.11
	Total	90	100

Following cone shape figure shows educational status of respondents.

Figure no 2.3



Above data interprets there are 13(14.44%) illiterate respondents. 22 (24.44%) numbers of individuals have taken primary education. The number of respondent who have completed Secondary /higher secondary are 55 (61.11%).

As per the observation table shown the 61.11% respondents who has taken secondary and higher education having low adherence.

Marital Status:

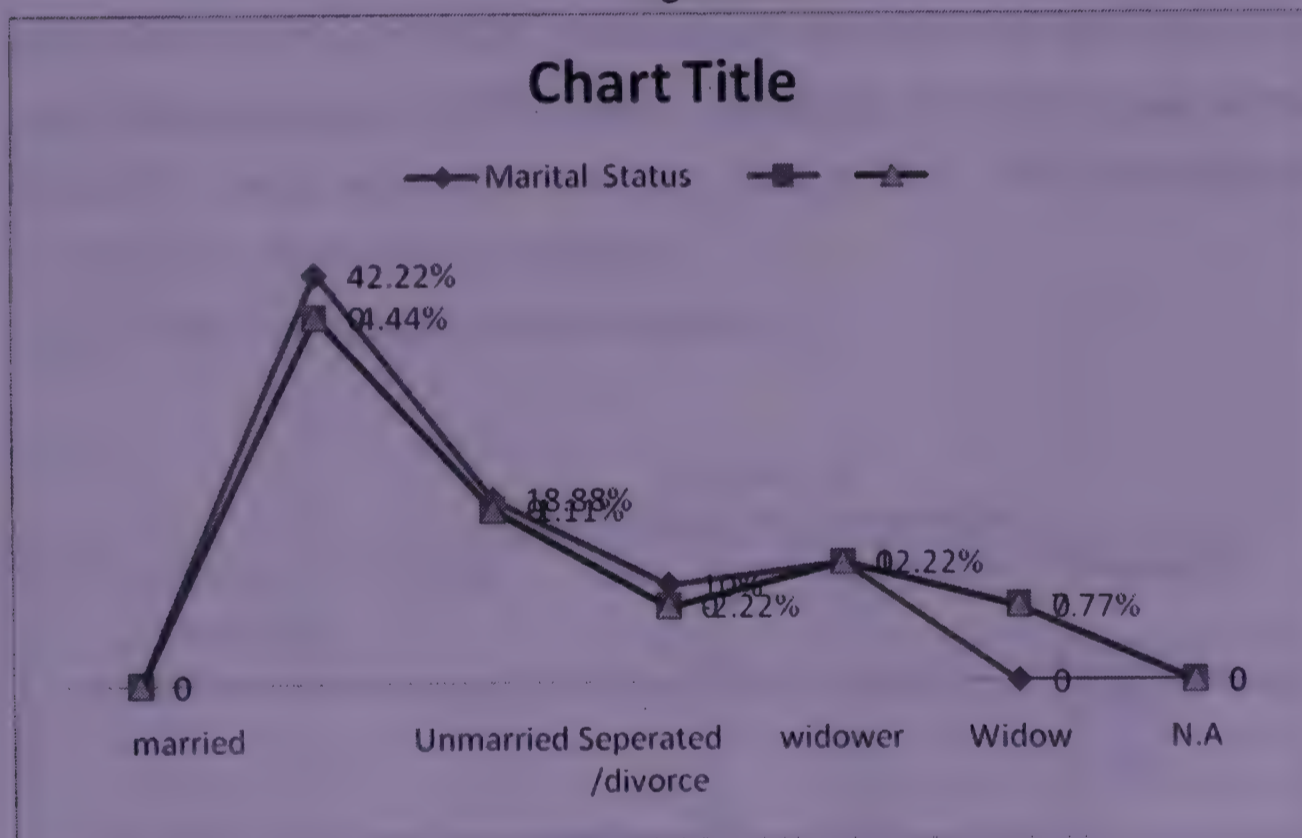
The marital status of an individual bestows up on one many a responsibilities. Does this status has any impact on the adherence was a question researchers mind, hence the researcher includes this point too.

Table 2.4
Marital Status of respondent

Sr. no	Marital Status	Male	Female	TG.
1	Married	38 (42.22%)	4(4.44%)	----
2	Unmarried	17(18.88%)	1(1.11%)	----
3	Seperated /divorce	9(10%)	2(2.22%)	----
4	Widower	11(12.22%)	---	----
5	Widow	----	7(7.77%)	----
6	N.A	----	----	1(1.11%)
	Total	75(83.33%)	14(14.55%)	1(1.11%)

Marital status of respondents shown in Line diagram.

Figure no 2.4



There are male 38 (42.22%) and 4(4.44%) female respondents who are married and 17 (18.88%) are unmarried male respondent. Only 1(1.11%) unmarried female respondent and 9(10%) number of male individuals are separated or divorce and 11 are widower. Female respondent are separated and widow 2(2.22%), 7 (7.77%) respectively.

The percentage of married individual is highest i.e. 42.22%.

Number of children

In modern times there is trend of small family. Planning is an important factor and the researcher wanted to know what the impact of this state of no children has on adherence to treatment.

Table 2.5
Respondents having number of .of children

Sr no	No.of children	Male	Female	T.G
1	None	16(17.77%)	1(1.11%)	
2	One	11(12.22%)	5(5.55%)	
3	Two	21(22.22%)	6(6.66%)	
4	Three and above	10(11.11%)	1(1.11%)	---
5	N.A	17(18.88%)	1(1.11%)	1(1.11%)
	Total	75	14	

N.A- 18 respondents are unmarried and 01 is transgender they are not applicable

For above table reveals that 16 (17.77%) male respondent and 1 (1.11%) female respondent is having no child. Respondents who have only one child is 11(12.22%) male respondent and 5 (5.55%) female respondent .21(22.22%) male respondent and 6 (6.66%) female respondent have two children.10(11.11%) male respondents and 1(1.1%) have three and above children.

22.22% male respondents have two children

Table no 2.6
Children staying with respondent

Sr no	children staying with respondent	No of respondents	Percentages
1	Yes	38	42.22%
2	No	17	18.88%
3	N.A.	35	38.88%
	Total	90	100

N.A- No of respondents are included unmarried respondent and other who not having Child.

From the above table it shows that 38(42.22%) respondents living with their children And 17 (18.88%) are staying separated from their children.

42.22%. childrens are staying with respondent.

Types of family:

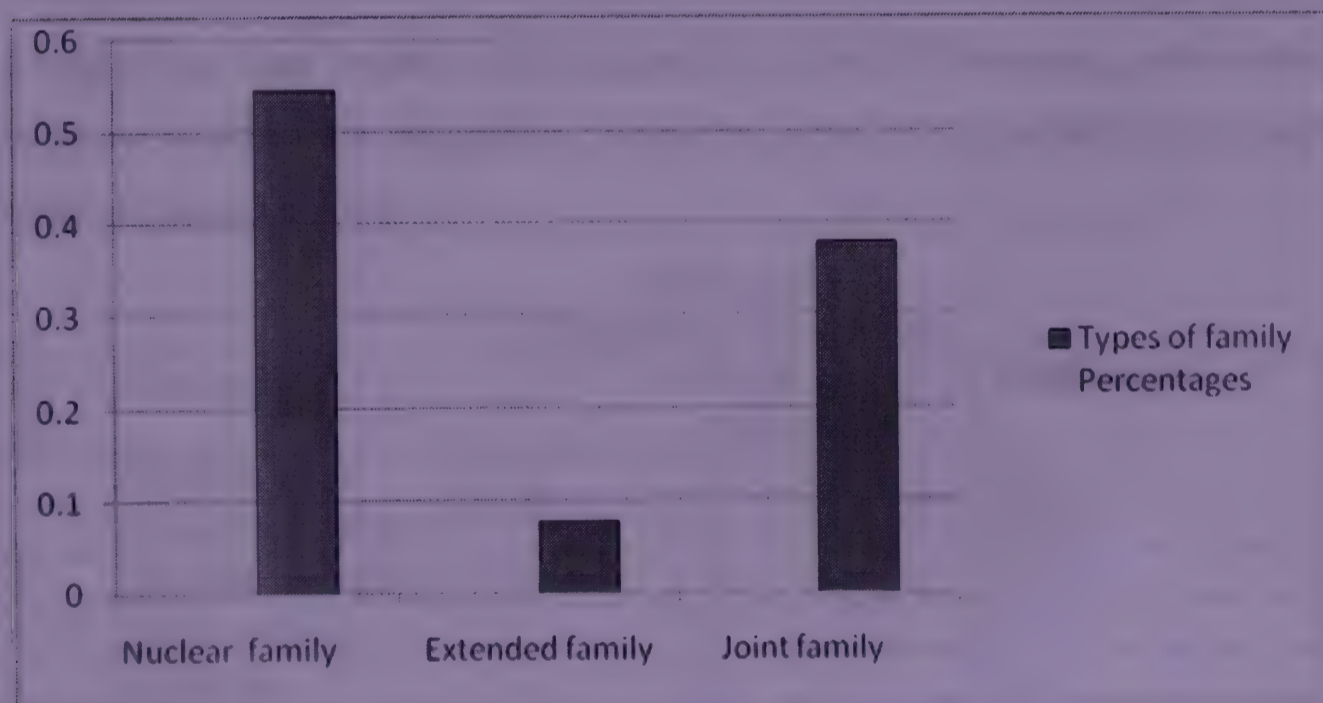
Family is a group of person united by ties of marriage, blood or adoption, consisting of single household, interacting and inter-communicating with each other in their respective social roles. Due to Globalization, there is trend of nuclear family, this question was originally posed in order to determine whether lack of privacy within the household affected patient medication adherence, as this is a known effect. On reflection, it would have also been important to ask if other members of the household knew of the patients HIV status in order to analysis this fully.. The researcher has tried to study relation between types of family and adherence.

Table no 2.7
Respondent family types

Sr. no	Types	No of respondents	Percentages
1	Nuclear family	49	54.44
2	Extended family	07	7.77
3	Joint family	34	37.77
	Total	90	100

Following column shape figure depict the types of family of respondents.

Figure no 2.5



The above figure shows that 49 (54.44%) respondents have Nuclear family . 34 (37.77) living in joint family and only 7 (7.77%) resides in extended family. Poorer medication adherence is seen in those living in nuclear family .i e 54.44%.

Employment :-

Employment means an individual who is in job and earns regular salary .Thus that individual knows what his income is and how much he should spend on what. Here the education helps him to plan his responsibilities and his income. This is not the case with the daily wages workers, or other occupations that are seasonal. However being employed in productive work promotes health. Here researcher considered employment means respondent worked in Fixed Time schedule with a regular salary.

Table no 2.8
Respondent Employed

Sr no	Employed	No of respondents	Percentages
1	Yes	24	26.66
2	No	66	67.77
3	Total	90	100

Above table revealed that 24(26.66%) respondent are employed.

and the number of respondent who are not employed is 66(67.33%).

67.77% respondent are not employed.

Occupation:-

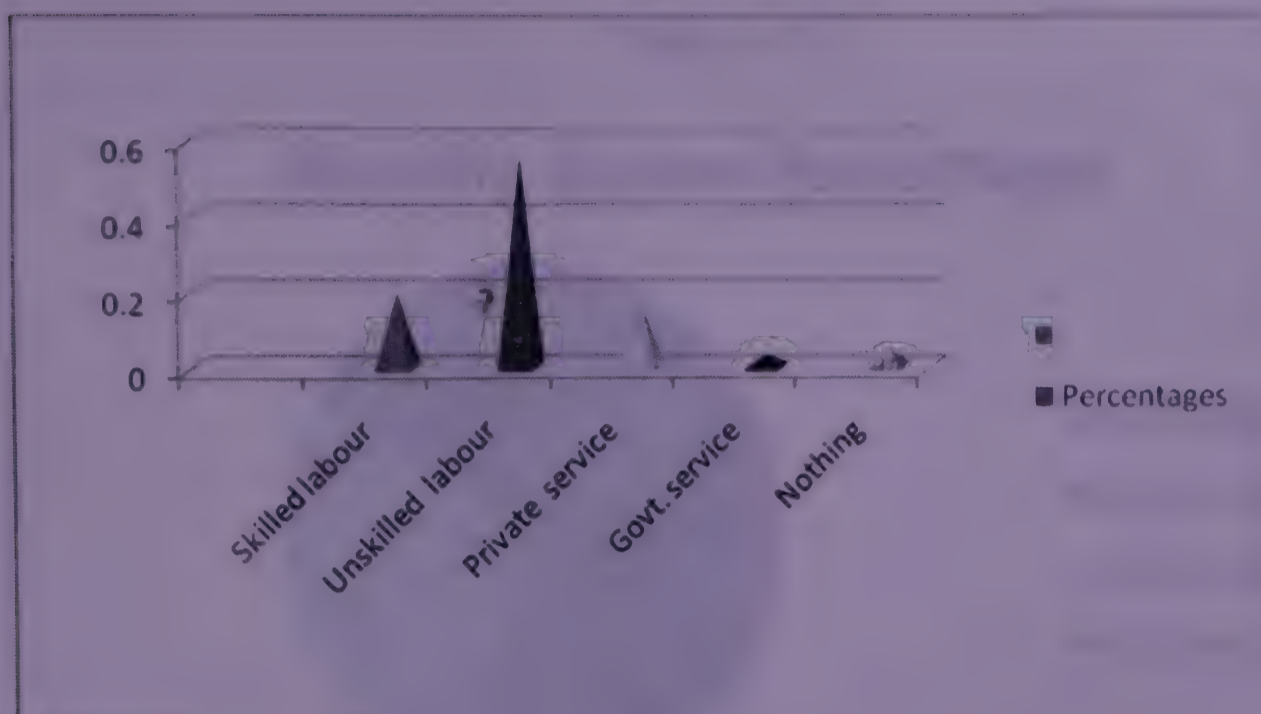
Occupation is also affects some aspects of the life of an individual. Due to occupation a person can think broadly and his capacity to think of becoming more mature. Hence to know whether the occupation varies the views of respondents the researcher has taken up this as a point.

Table no 2.9
Respondent occupation

Sr. no	Occupation	No of respondents	Percentages
1	Skilled labor	18	20
2	Unskilled labor	50	55.55
3	Private service	14	15.55
4	Govt. service	03	3.33
5	Nothing	05	5.55
	Total	90	100

Following cone shape figure indicate the different occupation of respondents

Figure no 2.6



From the above table it is seen that 18 (20%) of the respondents are in the category of skilled labor. 50 (55.55%) of the respondents are in the category of unskilled labor. 14 (15.55%) respondents are in the private sector and 5 (5.55%) are having no jobs at all.

55.55% of the respondents are in the category of unskilled labor.

Monthly income:-

Income is most influencing factor in human life. Greater income better will be economic condition of a person or family. Poor income may either contribute directly to lower adherence by preoccupying the patient with more immediate concerns, or be an indirect indicator of low social support. Low income may prevent patients from easily accessing health care, transportation.

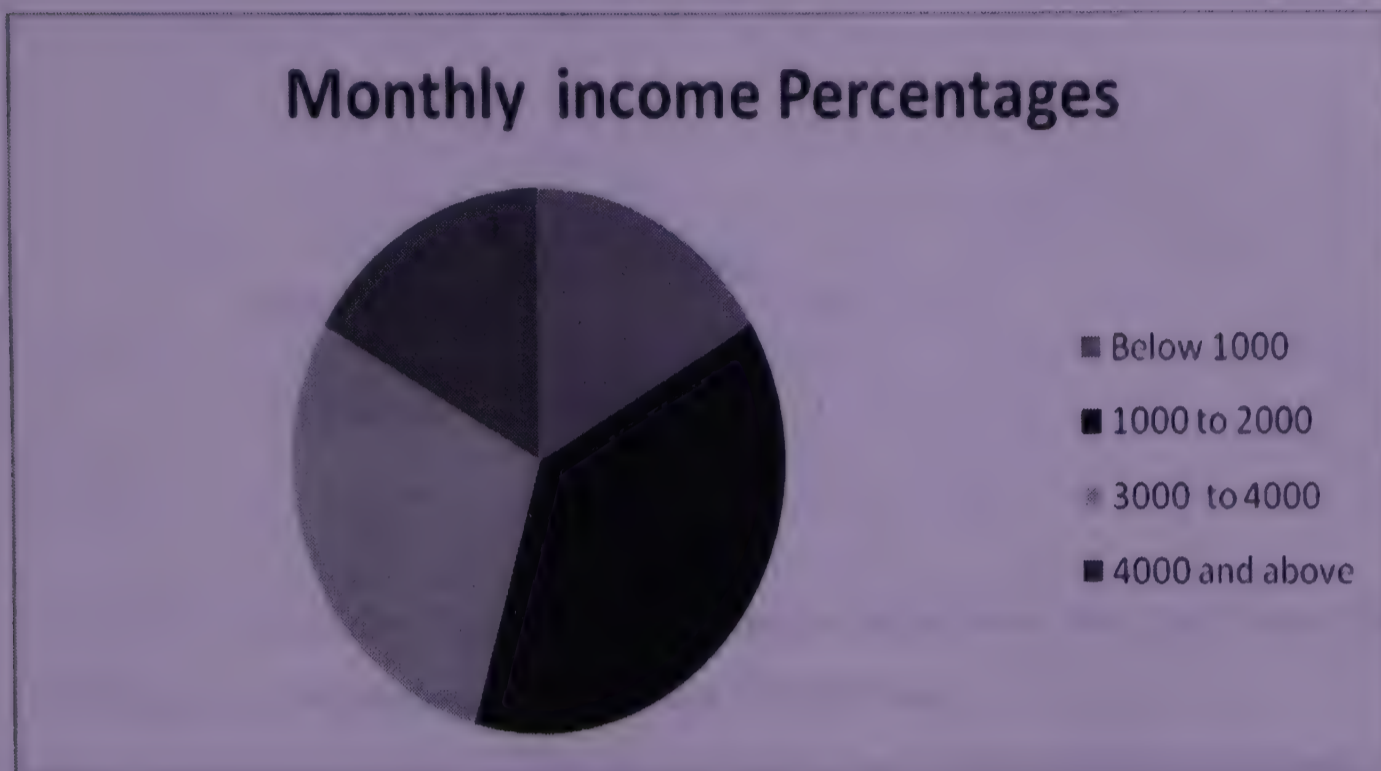
In order to know about the income (per month) of respondent, following table is prepared.

Table no 2.10
Monthly income of the respondent

Sr no	Monthly income	No of respondents	Percentages
1	Below 1000	15	16.66
2	1000 to 2000	34	37.77
3	3000 to 4000	26	28.88
4	4000 and above	15	16.66
	Total	90	100

Pie diagram me illustrate distribution of monthly income of respondents

Figure no 2.7



The above table shows that 15 (16.66%) respondent monthly income is below Rs.1000. 34 (37.77%) no of respondents are having a monthly income of Rs.1000 to 2000 and 26 (28.88%) respondent are earning monthly Rs 2000 to4000. 15(16.66%) respondents are having monthly income of Rs 4000 and above.

From above table conclude that 34(37.77%) respondent earned Rs1000 to 2000 monthly.

Ownership of home.

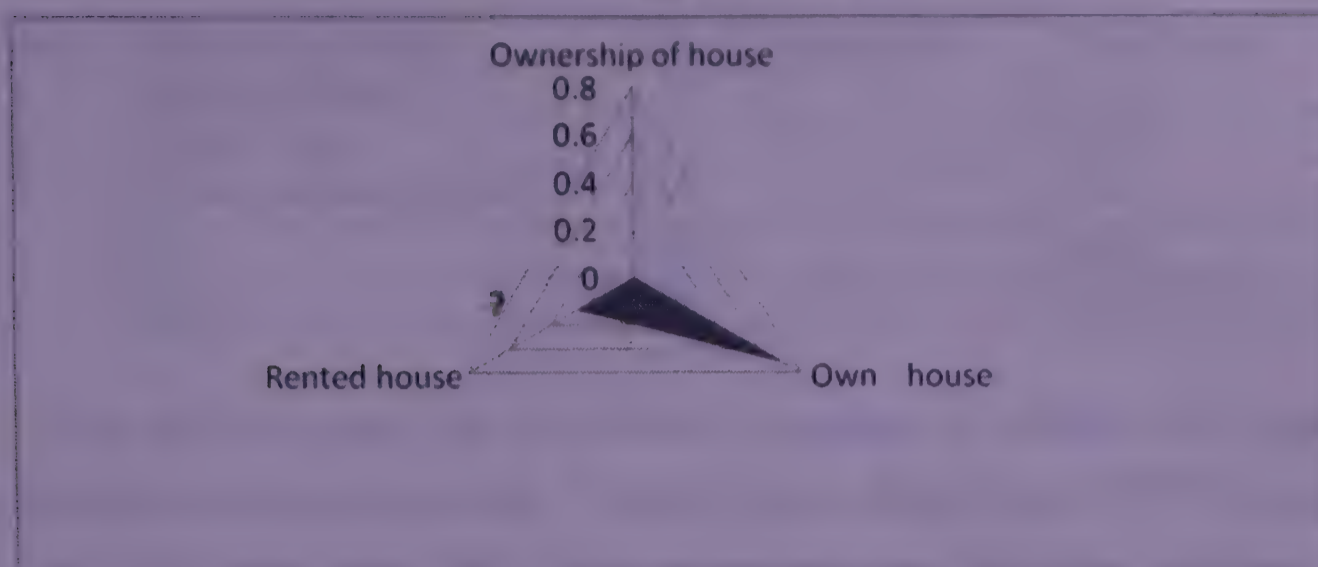
Having one's own house is a pleasant feeling which also gives a feeling of security in various ways. It is often symbolized as a good social status as well fair economic condition. Sometimes, especially when the HIV positive is living in a rented house there is a constant fear of being thrown out of the house which causes anxiety to a great extent. This is further harmful for the individual.

Table no 2.11

Sr no	Ownership of house	No of respondents	Percentages
1	Own house	65	72.22
2	Rented house	25	27.77
	Total	90	100

Following figure demonstrate the respondents residential status.

Figure no 2.8



The above table shows that 65 (72.22%) respondents have their own house But 25 (27.77%) no. of respondent are living in a rented house.

Major finding here is that 72.22% of respondents are living in their own houses.

Debt:

Unemployment is a major cause of low income and it leads to poverty, which in turn leads to low life style. The non availability of minimum essential food leads to poor health. The present social scenario of various attractions lead to negligence towards the basic needs and wrong eating habits add to the fuel. The low economic status thus becomes a cause to many unwanted hazards. Debt is one of them. To fulfill their needs people borrow money which they cannot pay easily and the interest goes on increasing.

Table no.2.12

Is the family in any kind of debt?

Sr no	Family in debt	No of respondents	Percentages
1	Yes	28	31.11
2	No	62	68.88
3	Total	90	100

The above table shows that 28(31.11%) respondents are under some or the other kind of debt. 62(68.88%) respondents have not procured any sort debt.

68.88% respondent are not under debt.

Table no 2.13

Debts are incurred by

Sr no	Debts are incurred	No of respondents	Percentages
1	helping relative	10	11.11
2	Taking loan	16	17.77
3	Selling ancient property	02	2.22
4	N.A	62	68.88
	Total	90	100

From above it is seen that 62 (68.88%) respondent are falling in the category who have got no debts of any sort. The above table shows that 16(17.77%) respondents have took some loan. 10(11.11%) respondents got help from relatives. 2(2.22) respondents have sold their property to return debt.

Duration of HIV status known:-

HIV test is done in ICTC, if the report is detected reactive the individual is registered at the ART centre. Testing positive for HIV means that now one carries the virus that causes AIDS. It does not mean that one has AIDS, nor does it means that he will die.

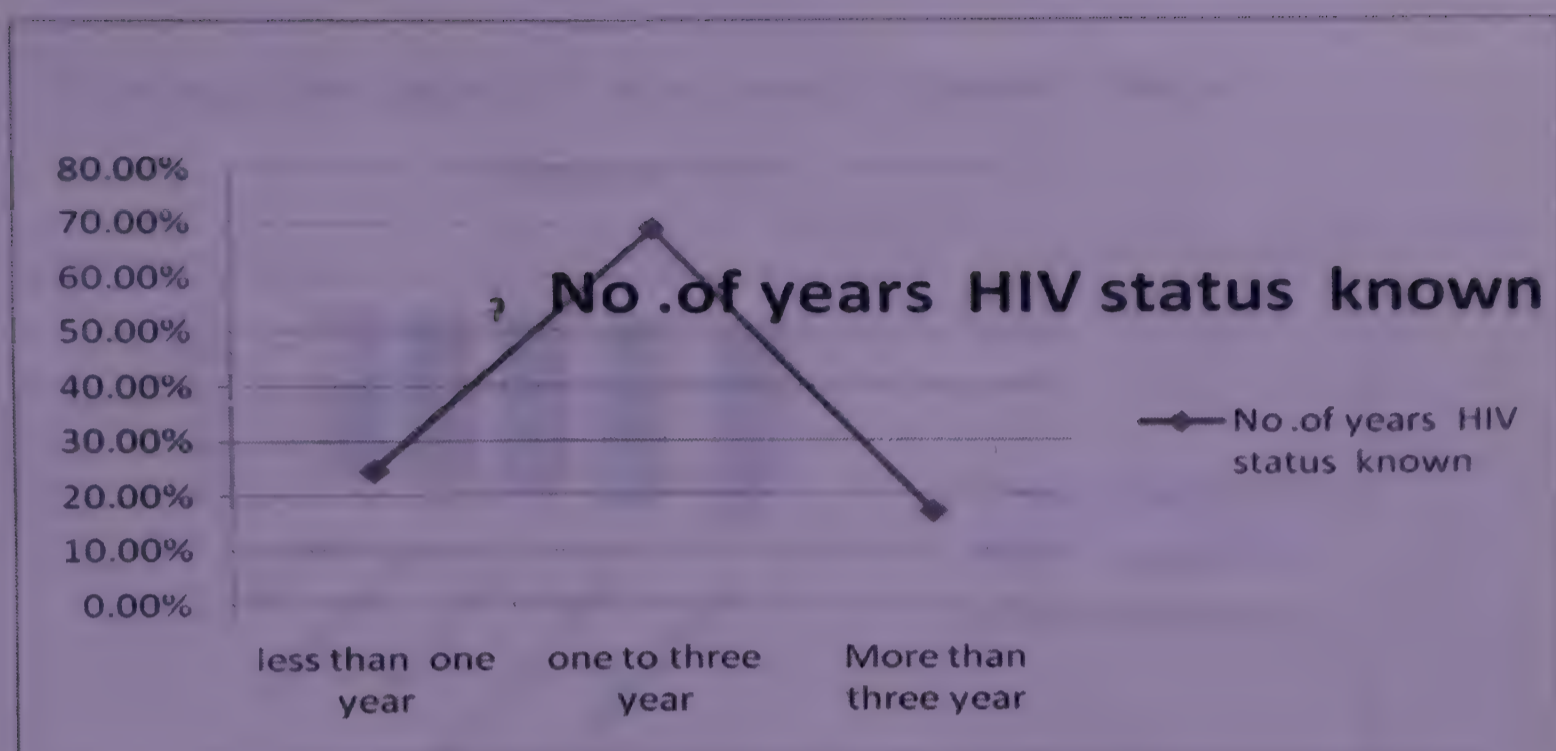
Figure no 2.14

No of years HIV status known of respondents

Sr.no	No .of years HIV status known	No of respondents	Percentages
1	less than one year	22	24.44
2	one to three year	62	68.88
3	More than three year	15	16.66
	Total	90	100

Following line diagram demonstrate duration of HIV status known of respondents

Figure no 2.9



The above data shows that 22(24.44%) respondents known their status before one year 62(68.88%) respondents are detected reactive between one to three year .No of respondent who came to know their status before three to four year are 15(16.66%). 68.88% Percentages of respondents came to know their HIV status reactive since a year to three.

HIV status known to

HIV status known to some PLHIV are extremely concerned with social stigma and discrimination. Many PLHIV have limited social support. In some cases, cultural or other factors may hinder the youth from disclosing it to their families, and some youth may be estranged from their families as a result due to a variety of issues.

Table no 2.15

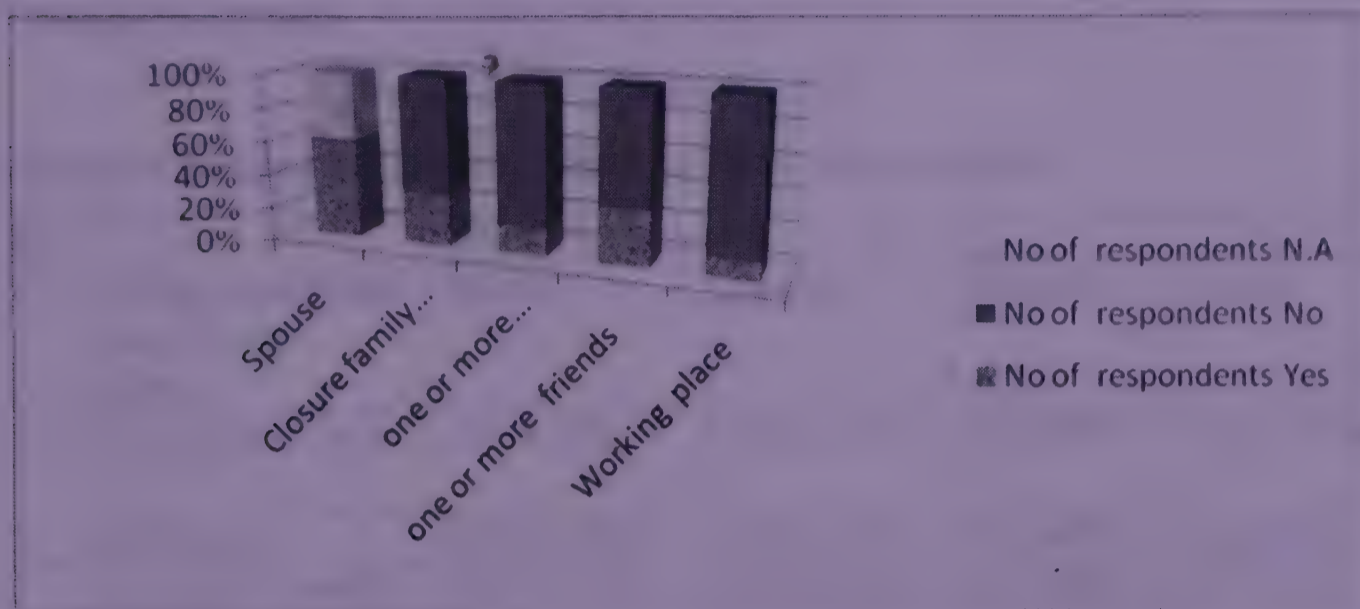
HIV status known to respondents close one .

Sr no	HIV status known to	No of respondents		
		Yes	No	N.A
1	Spouse	52(57.77%)	2(2.22%)	36(40%)
2	Closure family member	28(31.11%)	62(68.88%)	
3	one or more Neighbor	15(16.55%)	75(83.33%)	
4	one or more friends	30(33.33%)	60(66.66%)	

5	Working place	10(11.11%)	80(88.88%)	
	Total	90(100%)	90(100%)	

Following column diagram HIV status known to respondents close one .

Figure no. 2.10



N.A- 36 Respondents are not applicable as they are included as unmarried and widow/widower.

In this 52(57.77%) respondent revealed their status to their spouse. 28 (31.11%) respondents family member knew the status. 62(68.22%) respondent had not told their status to their close ones. Only 15(16.55%) respondents disclosed status to their neighbors but 75(83.33%) had not disclosed it to their neighbors. Less number of respondent i.e. 10(11.11%) revealed their status at their working place and 80(88.88%) respondent had not disclosed their status in working place.

Higher no of respondent not revealed their HIV Status to their close ones and relatives.

But 52.22% respondents spouses know the status.

Spouse status

Table no 2. 16

HIV status of Spouse of respondents

Sr no	spouse status	No of respondents	Percentages
1	HIV positive	39	53.33
2	HIV negative	16	17.77
3	Unknown	27	30.00
4	N.A	18	20
	Total	90	100

N.A.-18 (20%) respondents are not applicable as they are unmarried

From above data reveals that 39(53.33%) respondent partners status is HIV reactive and number of respondent whose spouse status HIV negative are 16 (17.77%) . 27(30%) respondents spouse status is undetected .

We conclude that 53.33% respondent's partner status is detected as HIV positive.

Change in attitude

Table No 2.17

Attitudes change after knowing status in Respondents relatives.

Sr no	Change in attitude towards the clients	No of respondent			
		Spouse	Family	Neighbor	Friend
1	Sympathetic /pity	15(16.66%)	10(11.11%)	2(2.22%)	12(13.33%)
2	Indifferent	10(11.11%)	03(3.33%)	4(4.44%)	6(6.66%)
3	pessimist towards patient	16(17.77%)	11(12.22%)	3(3.33%)	1(1.11%)
4	optimist towards patient	13(14.44%)	04(4.44%)	6(6.66%)	11(12.22%)
5	N.A.	36(40%)	62(68.88%)	75(83.33 %)	60(66.66%)
	Total	90(100%)	90(100%)	90(100%)	90(100%)

N.A.- No. of respondent not disclosed their HIV status to related one.

From above table it is obvious that 15(16.66%) respondents spouse, 10(11.11%) family member, 2(2.22%) neighbor and 12(13.33%) attitude sympathetic towards them .Indifferent attitude has been seen of 10 (11.11%.) spouse, 3(3.33%) family member, 4 (4.44%) neighbor and 6 (6.66%). 16(17.77%) spouse, 11 (12.22%) family member 3 (3.33%) neighbor are pessimist towards respondent. 13 (14.44%) spouse, 4 (4.44%) family, 6 (6.66%) neighbor and 11(12.22%) friends optimist towards the respondent.

Major finding is half of close ones attitude is positive towards respondents after knowing their status. 17.77% male respondents spouse attitudes is optimist towards the patient.

Behavioral change

Table no 2.18

Behavioral change after knowing status in Respondents closely related ones.

Sr no	Change in behavior	No of respondent			
		Spouse	Family/ relatives	Neighbor	Friend
1	Spouse left the house	12 (13.33%)	----	----	----
2	Angry /frustrated	19 (21.11%)	----	----	----
3	more caring	23 (25.55%)	----	----	----
4	Stopped to visit home	----	8 (8.88%)	----	----
5	Not invite in the function	----	2 (2.22%)	----	----
6	Not speaking	----	6(6.66%)	----	----
7	No change in the behavior	----	12 (13.33%)	6 (6.66%)	23 (25.55%)
8	totally cut relation	2(2.22%)	----	4(4.44%)	2(2.22%)
9	low frequency of visit	5 (5.55%)	----	3 (3.33%)	5 (5.55%)
10	Not attending the function	----	----	2 (2.22%)	----
11	No. of respondent not disclosed status to	36 (40%)	62 (68.88%)	75 (83.33%)	60 (66.66%)
	Total	90(100%)	90(100%)	90(100%))	90(100%)

23(25.55%) respondents spouse behavior more caring even after knowing status of partner but 12 (13.33%) and 19(21.11%) respondents spouse left the home and behaved in angry manner with the respondents.

No behavioral change in family member of respondent i.e. 12(12.33%) but 8(8.88%) respondents relatives stopped to visiting their homes, 2(2.22%) relatives did not invite respondents in their functions and 6(6.66%) family member even stopped to speak with respondent.

Neighbors of 6(6.66%)respondents got no change in behavior towards them even after knowing status but 4(4.44%) respondents neighbor totally cut relation , 3(3.33%) respondents neighbor frequency of visit respondents home is very less and 2(2.22%)

respondents neighbor did not attend function of respondents. 23(25.55%) number of respondents friends behavior did not change but 2(2.22%) and 5(5.55%) behaved indifferently after knowing respondents HIV status.

Major finding is that 13.33% and 21.11% respondents spouse behavior indifferent towards respondents .25.55% respondents friends behavior did change at all.

Discrimination

Any discrimination face in the employment place after knowing status

Discrimination at the work place has manifested thru attitudes of co workers as well as ranged from neglect, isolation avoiding close proximity abuse, teasing and name calling. It seem that if the status is known at the work place getting support from their employers.

Table no 2.19

No of respondent facing discrimination at working place.

Sr no	Face discrimination in the employment place	No of respondents	Percentages
1	No change in the behavior	15	16.66
2	not sharing food	2	2.22
3	neglect, isolation, abuse	8	8.88
4	No. of respondent not disclosed status to	77	85.5
	Total	90	100

From the above table it is observed that 4 (4.44%) of the respondents have seen no change in the behaviors of their collogues, 2 (2.22%) of the respondents faced the non- sharing of the food at the work place. 4 (4.44%) respondents faced the discrimination of abuse, isolation and neglect at the workplace.

A very high number 80 (88.88%) of respondents have not disclosed their status at their work place.

Major finding is half of friends not changed behavior towards respondents after knowing status.

Time of (Duration) starting ART therapy:

Table no 2.20

Time of starting ART therapy

Sr no	Time of starting ART therapy	No of respondents	Percentages
1	Less than one year	13	14.44
2	One to three year	65	72.22
3	More than three year	12	13.33
	Total	90	100

The above table shows that the maximum number of respondents i.e. 65 (72.22%) started ART within a period of one to three years. 13(14.44% respondents continue for less than one years and 12 (13.33%) respondents started therapy more than three year.

Being on ART for one to three years was associated with the largest number i.e. 72.22% respondent had missed medications.

Opportunistic infections

HIV positive people with suppressed immune systems may experience illnesses that are not usually seen (or do not cause symptoms) in people with healthy immune systems; these illnesses are called "opportunistic infections"

Table no.2.21

No of respondent having any opportunistic infection.

Sr no	At present having any opportunistic infection	No of respondents	Percentages
1	Yes	65	72.22
2	No	25	27.77
	Total	90	100

From the above table it is obvious that 65(72.22%) respondent suffered from some kind of opportunistic infection and only 25 (27.77%) did not have any O.I.s
A higher percentage of respondents suffered from some or the other kind of opportunistic infection is 72.22%.

Opportunistic infection.

Many OIs can be prevented or treated successfully. This has substantially increased the longevity and quality of life for people living with HIV/AIDS

Table no 2.22

No of respondent suffered from following opportunistic infection.

Sr no	opportunistics infection	No of respondents	Percentages
1	Pulmonary tuberculosis	2	2.22
2	Extrapulmonary tuberculosis	23	25.55
3	Herpes Zoster	9	10
4	Candidiasis	14	15.55
5	Diarrhoea	17	18.88
6	No of respondent not having Opportunistic infection	25	27.77
	Total	90	100

The above table depicts that 2 (2.22%) of respondents were suffering from pulmonary tuberculosis. 23(25.55%) of respondents had extrapulmonary tuberculosis, 14(15.55%) respondents had candidiasis, 17(18.88%) were suffering from Diarrhoea. The rest of 25(27.77%) did not have any kind of O.I.s.

25.55 percentages of respondents are suffering from extra pulmonary tuberculosis.

Regular CD 4 counts done.

After HIV reactive diagnosis, it is necessary to do CD4 test after regular interval. New guidelines recently issued by the U.S. Department of Health and Human Services indicate that initial treatment be considered for patients with CD4 cell counts less than 350.

Table no 2.23

No of respondent done regular CD4 counts.

Sr no	Regular CD4 counts done .	No of respondents	Percentages
1	Yes	70	77.77
2	No	20	22.22
	Total	90	100

From above data it concludes that 70(77.77%) respondents done CD4 regularly but 20(22.22%) respondents not done CD4 regularly.

Last CD4 count

CD4 count indicates immune suppression. After starting ART therapy. CD4 test should be done every six months. This helps to monitor the immunological system of the individual.

Table No 2.24

Last CD4 count of respondent

Sr no	CD4 count	No of respondents	Percentages
1	Between 1 to 50	11	12.22
2	50 to 100	12	13.33
3	100 to 150	38	42.22
4	150 to above	29	32.22
	Total	90	100

From the above data it is obvious that 11(12.22%) respondent CD4 count is between 1 to 50. No of respondents having CD4 count between 50 to 100 is 12(13.33%), 38(42.22%) respondents CD4 count is between 100 to 150 and 29(32.22%) respondents CD4 count is 150 to above.

Major finding is 42.22% respondents having CD4 count is between 100 to 150.

Belief in HIV therapy

Patient's strong belief in the treatment, and effective involvement of patients acts as active agents in their own care and treatment. Negative attitudes about medications or illness may also interfere with patient adherence. Amongst the mentally ill, reasons cited for not taking medications were fear of addiction and the belief that medication use was a sign of weakness.

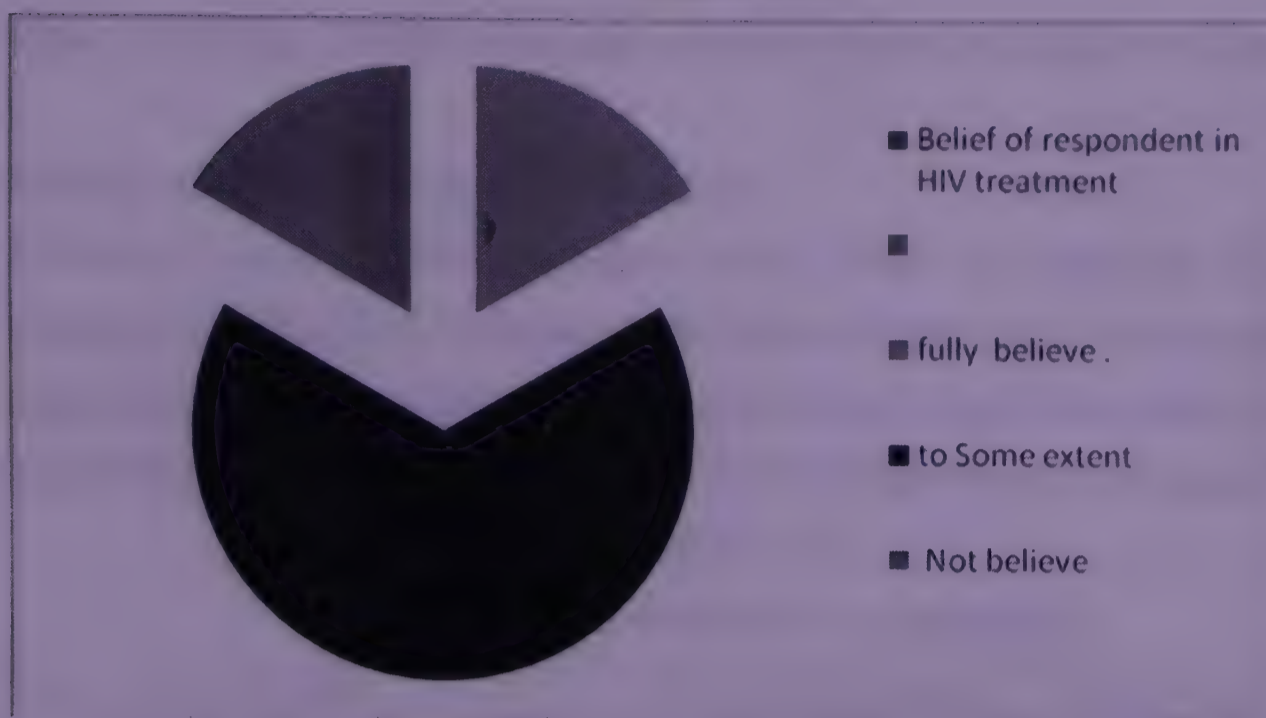
Table no 2.25

Belief of respondent in HIV treatment

Sr no	Believe in HIV therapy	No of respondents	Percentages
1	fully believe .	15	16.66
2	to Some extent	60	66.66
3	Not believe	15	16.66
	Total	90	100

Pie diagram indicates the number of respondent belief in HIV treatment

Figure 2.11



15(16.66%) respondent totally believe in HIV therapy and 15(16.66%) not believe 60(66.66%) respondents believe in some extent.

Major percentage of i.e. 66.66% respondents belief in ART are not confident about the therapy.

Satisfaction:

Negative characteristics of particular medication regimens are common barriers to adherence. Respondents who feel healthy before starting ARVs will be very unlikely to accept having significant side effects, especially if they last more than a week or two the patient's perception of how beneficial treatment would be in affecting illness outcome was also associated with compliance. Amongst HIV infected patients, attitudes and beliefs related to decreased adherence included the patient's acceptance/perception of disease.

Table No 2.26

Respondent satisfied with health after ART therapy

Sr no	Respondent satisfied with health after ART therapy	No of respondents	Percentages
1	Dissatisfied	36	40.00
2	Satisfied	51	56.66
3	cant say	03	3.33
	Total	90	100

36(40%) respondents dissatisfied after initiating ART and 51(56.66%) respondents totally satisfied due to ART treatment but 3(3.33%) respondents not given response to this question.

Major percentages 56.66% respondents feeling of satisfaction due to treatment.

Strategy used to remember to taking dose

A buddy or accompagnateur, usually a relative, friend, or community volunteer who completes regular, direct observation and documentation of the patient taking his/her medication. A helper, a well-trained volunteer who 'walks' exclusively with a client in providing comprehensive support, which includes ensuring to adherence.

Table No 2.27

Strategy used to remember to taking dose

Sr no	strategy used	No of respondents	Percentages
1	Pill diary	1	1.11
2	Calendar	2	2.22
3	Reminds by Spouse /family member	30	33.33
4	Alarm	14	15.55
5	Self reminds without using any strategy	43	47.77
	Total	90	100

1 (1.11%) respondent use pill diary as a reminder for ART medicine.

2 (2.22%) respondents write on calendar for taking dose. The respondents, whose family member or spouse reminds them every day to take their medicine i.e 30(33.33%). 14 (15.55%) reminds by setting a alarm in watch or mobile. 43(47.77%) respondents take medicine on self reminders.

Percentages of respondents is higher, those who take doses of ART without using any strategy ie .47.77.

Side effects when initiated ART therapy

Those who experience side-effects from their medications are known to be 'risk patients' for non-adherence to ART. However, the severity of the side effects also seemed to be a factor. Those experiencing milder side effects such as skin rash or skin discoloration were more adherent to ART than those experiencing more severe side effects such as metabolic effects.

Table no.2.28

Respondent suffer from side effects when initiated ART therapy.

Sr no	suffer from any side effects	No of respondents	Percentages
1	Yes.	72	80.00
2	No.	18	20
3	Total	90	100

From the above table it is observed that 72(80%) respondents have suffered some kind of side effect from the ART therapy. 18 (20%) respondents had no side effects after initiating the ART therapy.

Major portion of the respondents i.e. 80 % suffer from some or the other kind of side effects from the ART therapy.

Side effects

Table no 2.29

Respondents suffered from following side effects

Sr no	side effects	No of respondents	Percentages
1	Anemia	08	8.88
2	Skin rash	03	3.33
3	Peripheral neuropathy	08	8.88
4	Nausea/vomiting	30	33.33
5	Lipodipathy	03	3.33
6	Loose motion	14	15.55
7	Dizziness/insomnia /nightmare, suicidal ideation	06	6.66
8	No of respondent not having side effects	18	20
	Total	90	100

No of respondents 8(8.88%) were suffering from anemia when initiation ART.

30(33.33%) respondents having feeling of nausea /vomiting and 3(3.33%) respondents were having skin rashes and those Lipodipathy. 14(14.44) had a complaint of loose motions. Major finding is that 33.33% respondents having feeling of nausea /vomiting after initiating ART.

Frequency of missing doses

Table no.2.30

No of respondent missed dose as for following period

Sr no	Frequency of missing dose	No of respondents	Percentage
1	Single dose	02	2.22
2	More than 2 days	12	13.33
3	More than 15 days	60	66.66
4	More than 3 months	16	17.77
	Total	90	100

From the above table it is seen that the 60(66.66%) of the respondents were such that they had missed there medicine doses for more than 15 days, 16(17.77%) respondents were such that they had missed there medicines for more than three months, there also such respondents who had missed the dose for two days, and only 2 (2.225) respondents were such that had missed a single dose.

66.66% of respondents were such that who had missed their ART dose for more than 15 days.

The causes which give rise to the psychological problems which are responsible for missed doses of ART.

Table no. 2.31

Sr no	psychological problems	No of respondents	Percentages
1	depression/stress after knowing status	16	17.77
2	Fear of side effects	08	8.88
3	Recurrence of Opportunistic infection	8	8.88
4	pill burden	10	11.11
5	Differences with spouse or family member	20	22.22
6	Depression due to Lost of /partner and living alone	08	8.88
7	Addiction of Alcohol and substance	14	15.55
8	change in daily routine life style	06	6.66
	Total	90	100

It seems that the number of respondents missing doses has was high due the differences with spouse or family member i.e. 20 (22.22%). Next to this, the cause was pill burden 10 (11.11%), followed by 14(15.55%) no of respondent missed doses

due to addiction of alcohol and other substances and lastly depression and stress caused 16 (17.77%) respondents to miss their doses.

This is obvious from the response percentage that 22.22% respondents having differences with spouse or family member is be greatest cause of psychological problem.

Social problems which is cause to discontinue the ART treatment.

These factors and some of the attendant negative aspects that could interfere with treatment adherence.

Table no 2.32

No of respondent face following social problem

Sr no	Social problems	No of respondents	Percentages
1	Social stigma ,fear of disclosure HIV status	04	4.44
2	limited faith in the treatment	19	21.11
3	Lack of family and social support	30	33.33
4	Financial constraints/travel costs	06	6.66
5	Migration and frequent traveling for employment	20	22.22
6	Loosing daily wages	05	5.55
7	Not getting leave from working place	02	2.22
8	Just forget due to busy schedule	03	3.33
	Total	90	100

From the above table we observe that there are 4 (4.44%) respondents who face HIV as a social stigma, 19(21.11%) respondents have limited faith in treatment. 30(33.33%) respondents didn't got the family or social support. 6(6.66%) respondents faced financial constraints. 20(22.22%) respondents migrated due to employment, 5(5.55%) respondents loose daily wages, 2 (2.22%) didn't got leave from their working place and 3 (3.33%) missed dose as they just forget.

ART centre

In Maharashtra there are total 44 ART centre, each district have a minimum one ART centre, which is situated in the Government hospital where they are given a separate premises for ART center. So sometimes fears to come to the centre as they fear that some known person or relative will be meet them and their status will be disclosed. Working hours of ART centre is mostly the same as the work time of others working hours at the office therefore there is a loss one day wages.

Table no .2.33

Difficulties faced in ART centre to continue the ART treatment

Sr no	Difficulties in ART centre	No of respondents	Percentages
1	Yes	75	83.33
2	No	15	16.66
	Total	90	100

From above table data shows that 75(83.33%) respondents face difficulties at the ART centre to continue their medication and 15(16.66%) respondents did not have any problem in ART centre.

83.33% respondents were having difficulty at the ART centre to continue with the medication.

Table no 2.34

Difficulties faced by respondent to continue the treatment in ART centre

Sr no	Difficulties to continue the ART treatment	No of respondents	Percentages
1	Time consuming	61	67.77
2	Discriminatively behavior from health care provider.	2	2.22
3	Fear of recognition HIV status in ART centre	12	13.33
4	N.A	15	16.66
	Total	90	100

61(67.77%) respondents replied that a lot of time is consumed at the ART centre.

2(2.22%) respondents replied that they faced discriminative behavior from health care provider and 12(13.33%) respondent had feared of recognition of their HIV status at ART centre. 15(16.66%) respondents did not face any problem in ART centre .

Time consumed at ART centre was very high was the response of 67.77% respondents as main cause to continue medication from the ART centre.

Relation between duration of HIV therapy and psychological barrier

Table No 2.35

The following table showing relation between duration of HIV therapy and psychological barrier

Sr	Duration of treatment	Psychological barriers								Total
		depression/stress after	Fear of side effects	Recurrence of opportunistic	Pill burden	Differences with spouse or family member	Depression due to loss of Partner or	Addiction of Alcohol and	Change in routine life	
1	less than one year	5 38.46 %	3 23.07 %	2 15.38 %	--	--	--	2 15.38 %	1 7.69%	13(100%)
2	one to three year	10 1.53%	5 7.69%	4 6.15%	8 12.30%	17 26.15%	6 9.23%	12 18.46 %	3 4.61%	65(100%)
3	More than three year	1 8.33%	----	2 16.66 %	2 16.66%	2 16.66%	2 16.66%	----	2 16.66 %	12(100%)
	Total	16 17.77 %	8 8.88%	8 8.88%	10 11.11%	20 22.22%	8 8.88%	14 15.55 %	6 6.66%	90(100%)

($\chi^2 = 15.10$, $df = 14$, $Assy.Sig = 23.69$, $6 = 0.05$)

From the above data out of 100 respondents, 33.46 respondents who started Treatment less than one Year having depression /stress .23.07 percetanges of respondents whose initiation of Treatment Period is less than one year having fear of side effects. 15.38% respondents whose initiation of treatment period is less than one year were having high recurrence of opportunistic infections.

15.38% respondents who started treatment less than year are addicted alcohol.

10 (1.53%) out of 65(100%) whose initiation of treatment period is less than three years. Having depression and stress there were 7.69% respondents who started treatment less than three year having fear of side effects. 7.69% respondents whose initiation of treatment period is One to three year having recurrence of opportunistic

infection. 26.15 percentage respondent whose initiation of treatment period is one three year was having differences with spouse /family member 2(16.66%) out of 12 (100%) respondents whose initiation of treatment period is more than three year having differences with family member ,depression due to loss of partner and low adherence due to Changing life styles.

In the table the Chi-square value is 15.10, degree of freedom is 14 and Assy sig. is 23.69. Here is chi square value is less than table value means accept null hypothesis, there is a relationship not existed between duration of treatment and psychological barrier.

Relation between duration of HIV therapy and social barrier

Table No. 2.36

The following table showing relation between duration of HIV therapy and social barrier

Sr n o	No .of years HIV therapy	Social stigma ,fear of	Limited faith in treatment	Lack of family support	Financial constraint and Travel cost	Migration and frequent travelling for	Loosing daily wages	Not getting leave from working place	Just forgot ,due to function	Total
1	less than one year	2 15.38 %	4 30.76%	3 23.07%	--	--	2 15.38%	2 15.38%		13 (100%)
2	one to three year	2 3.07 %	13 20%	25 38.46%	4 6.15%	15 23.07%	2 3.07%		3 1.53%	65 (100%)
3	More than three year		2 18.18%	2 18.18%	2 18.18%	5 45.45%	1 9.095			12 (100%)
	Total	4 (4.44 %)	19 21.11%	30 33.33%	6 6.66%	20 22.22%	5 5.55%	2 2.22%	3 3.33%	90 (100%)

($\chi^2 = 25.7$ df=14, Sign. Table value = 23.69, $\alpha = 0.05$).

Facing social stigma, fear of disclosure HIV status 15.38 percentage of respondents whose initiation of treatment period is less than one year. Having limited in treatment 30.76% of respondents whose initiation of ART less than one year. 23.07% respondents have lack of family support whose treatment period is less than one year.

15.38% respondents who started treatment less than year are facing problem i.e. losing their daily wages and not getting leave from working place. 3.07 % respondents whose initiation of treatment period is one to three year facing social stigma and losing daily wages which is cause of low adherence. Whose initiation of treatment period is one three year having and lack of family support is 38.46%. 2(18.88%) out of 12(100%) respondents whose initiation of treatment period is more than three year having lack of family support , limited faith in treatment and financial constraints. 45.45% respondents whose initiation period was of more than treatment, more than three year having low adherence because of frequent travelling for employment.

In the table the Chi-square value is 25.7, degree of freedom is 14 and Assy Sig. is 23.69. Here is chi square value is more than table value means reject null hypothesis, Test clearly shows statically significant relationship existed between duration of treatment and social barriers.

Respondent membership

There are two Network of HIV Positive people established in India , One is INP+ (Indian network of Positive people) and the other is PWN+ (Positive Women Network). There are district level Network in every district. Network providing services to client as according to need which when arises. In network people make support group as voluntarily.

Table no 2.37

Member of any support group of any organization

Sr no	member of any support group of any organization	No of respondents	Percentages
1	Yes	20	22.22
2	No	70	77.77
3	Total	90	100

Above table shows that only 20(22.22%) respondent are member of network 70(77.77%) respondent are not showing any interest to get connected with any organization, 77.77% respondent were not members of any support group which are initiated by NGO.

Initiation of support group by NGO

Table no 2.38

No of respondents having membership in some NGO.

Sr no	Initiation of support group by NGO	No of respondents	Percentages
1	Network of Nagpur people living with HIV (NNP+)	12	13.33
2	Positive women network of Maharashtra (MPWN+)	02	2.22
3	Religious organization	04	4.44
4	Any other NGO(YMCA,IRCS)	02	2.22
5	No of respondent not member of any Network	70	77.77
	Total	90	100

12 (13.33%) respondents are member of support group of Network of Nagpur people living with HIV (NNP+) and 2(2.2%) respondent are member of Positive women network of Maharashtra. 4(4.44%) are member of support group of religious organization.

2 (2.22%). Number of respondent were members of a Network (YMCA, IRCS)
13.33% respondents are member of support group of Network of Nagpur people living with HIV (NNP+).

Frequency of visit in network

PLWHA support groups can be a source of weekly support sessions.

Encourage the peer participation and help treatment support person.

Table no 2.39

Frequency of visit to meeting in peer group /Support group.

Sr no	Frequency of visit to meeting in peer group	No of respondents	Percentages
1	Once in month	08	8.88
2	Rarely	12	13.33
3	No of respondent not member of any Network	70	77.77
	Total	90	100

From above table reveals that 8(8.88%) respondents showed interest to participate in monthly meeting held by various NGOs 12 (13.33%) no of respondent visited rarely

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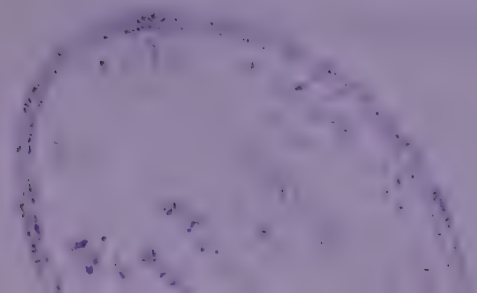
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at the office of the NGOs, where as only 8.88% visited regularly in monthly support group meeting of Network.

Duration of membership

Table no 2.40

Duration of membership with support group /network

Sr no	Duration of membership	No of respondents	Percentages
1	less than 3 month	02	2.22
2	3 to 6 months	04	4.44
3	6 to 12 months	12	13.33
4	12 months and Above	02	2.22
5	No of respondent not member of any Network	70	77.77
	Total	90	100%

From above table it is obvious that 2(2.22%) respondents join in network before three month. 4(4.44%) respondents networking with NGO since three to six month, the 12(13.33%) number of respondents were members from the duration of six months to one year. Only 2(2.22%) respondents were having membership for above a year. 70(77.77%) respondents did not join any group.

Social support provided from Network

Table no 2.41

Social support provided from Network/organization.

Sr no	Social support provided from Network	No of respondents	Percentages
1	home Visit by member	16	17.77
2	help in the illness	02	2.22
3	help to get in admission in hospital.	02	2.22
4	No of respondent not member of any Network	70	77.77
	Total	90	100

16(17.77%) respondents said that they gained support from networks home visit by a member of the network. 2(2.22%) respondents got assistance by support group member during their illness. 2(2.22%) respondents got the facility from a network to



get admission in hospital by network. Networks provided social support to 17.77% of respondents through home visits by network people.

Emotional support provided by Network.

Table No. 2.42

Emotional support provided from Network/organization

Sr no	Emotional support provided from Network	No of respondents	Percentages
1	Counselling	12	13.33
2	sharing the experience	02	2.22
3	Companionship	04	4.44
4	hope/motivation	02	2.22
5	No of respondent not member of any Network	70	77.77
	Total	90	100

12(13.33%) respondents gained emotional support from network through counseling by a support group member. 2(2.22%) respondents got assisted by peer a group member in sharing their experience. 4(4.44%) respondents were aided with emotional support through companionship. 2(2.22%) respondent were given hope /motivation in by network network people, other 2 (2.22%) were provided emotional support to respondents through counseling.

Legal support

SAATHII (Solidarity And Action Against The HIV Infection In India) and PWN+ provide services in advocacy initiatives, legal literacy, legal service referrals, follow up on litigations and establish and maintain linkages with the legal aid cells and other local service providers. HRLN (Human Rights Legal Network) also fights to protect human rights.

Table no 2.43

Legal support provided from Network/organization

Sr no	Legal support provided from Network	No of respondents	Percentages
1	provide information about Human rights /health rights	13	14.44
2	provide information about Right to Information./PIL	05	5.55
3	support to fight in the legal matter	02	2.22

4	No of respondent not member of any Network	70	77.77
	Total	90	100

13(14.44%) and 5(5.55%) respondents attend legal literacy workshop where they receive information about human rights and RTI/PIL respectively. 2(2.22%) respondents received help from Network in their legal matters. Number of beneficiaries in legal literacy is very less.

Economical Support

Many religious NGOs provide ration to poor PLHIV (people living with HIV). Positive Women Network is providing training to Women for income generation. One NGO is running a CHAHA project which helps to build the economical support to CLHA Parents.

Table No.2.44

Economical support provided from Network/organization

Sr no	Economical support provided from Network	No of respondents	Percentages
1	Provide nutrition/rationing	16	17.77
2	Giving information about financial resources	02	2.22
3	Training of Income Generating Programme	02	2.22
4	No of respondent not member of NGO/network	70	77.77
	Total	90	100

16(17.77%) respondent were receiving ration from religious NGO. Some Networks provided information about financial resources and referral services to 2(2.22%) respondents and 2(2.22%) No of respondent got benefit of training of income generating programme.

Awareness among respondents.

Table no 2.45

No of respondent having knowledge about treatment.

Sr. No	Awareness/Knowledge	No of respondent			Total
		Yes	No	Cant Say	90(100%)
1	Difference between HIV/AIDS	34(37.77%)	42(46.66%)	14(15.55%)	90(100%)
2	Awareness about opportunistic infection	46(51.11%)	44(48.88%)	---	90(100%)
3	Knowledge about function/effects of ART	24(26.66%)	63(70%)	03(3.33%)	90(100%)
4	Awareness about importance of adherence of ART	38(42.22%)	12(13.33%)	40(44.44%)	90(100%)
5	information about side effects and its management	49(54.44%)	41(45.55%)	----	90(100%)

From the above table it is seen that the 34(37.77%) respondent knew difference between HIV and AIDS. 42(46.66%) and 14(15.55%) are not having knowledge about HIV and AIDS. No of respondent not aware about 44(48.88%) opportunistic infection. 63(70%) respondent did not know how the ART functions. 38(42.22%) respondent have knowledge the importance of adherence. 49(54.44%) respondents were informed about side effects of the ART therapy. 41(45.55%) of the respondents were not aware of the ART therapy side effects.

Major findings is that 62% of the respondents are not having any knowledge about the difference between HIV and AIDS. 51.11%. of respondent are not aware about what opportunistic infection are? 70% respondents not know how the ART functions. 54.44% respondents were informed about side effects of the ART therapy. 54.44% of the respondents were aware of the ART therapy side effects.

Chapter –III

A. MAJOR FINDINGS

B. CONCLUSION

C. SUGGESTIONS

Major findings:-

1. 57.77% respondent belonging to 25 to 35 years is the highest group having low adherence 83.33% male respondents are having highest low adherence.
2. 61.11% respondents who has taken secondary and higher education were seen to have low adherence.
3. The percentage of married individual is highest i.e. 42.22%.
4. Poorer medication adherence is seen in those living in nuclear family i.e. 54.44%.
5. 67.77 percentages respondents are unemployed.
6. 55.55% of the respondents are in the category of unskilled labor.
7. 37.77% respondents earn a monthly income of Rs1000 to 2000.
8. 72.22% of respondents live in their own houses.
9. 68.88% respondents have not procured any sort of debt.
10. 72.22% respondent came to know about their HIV status in one to three year.
11. 57.77% respondents revealed their status to their spouses. 68.22% respondents did not disclose their status to their close/near ones. 83.33% respondents have not told about their status in their neighborhood. 80(88.88%) respondent not disclosed their status at their working place.
12. 53.33% respondent's had their spouses status detected, which was HIV positive.
13. 17.77% of male respondents spouse attitudes was optimistic towards respondents after knowing status, one major finding is that half of close near ones attitude is positive towards respondents after knowing the status.
14. Major finding is that 13.33% and 21.11% respondents spouse behavior indifferent towards respondents. 25.55% respondents friends behavior did change at all.
15. Major finding is half of the friends behavior was not changed towards respondents after knowing their status.
16. A higher percentage of respondents suffered from some or the other kind of opportunistic infection that is 72.22%.
17. 25.55 percentages of respondents were suffering from extra pulmonary tuberculosis
18. Major finding is 42.22% respondents were having CD4 count between 100 to 150.
19. Major percentage i.e. 66.66% respondents are not confident about the ART treatment.

20. Major percentages 56.66% respondents have feeling of satisfaction due to treatment they receive.
21. 74.44% of respondents were initiation of ART was one to three year were associated with the largest number of respondents who had missed medications.
22. Major portion of the respondents i.e. 80 % suffer from some or the other kind of side effects from the ART_T therapy.
23. 7.77% respondents are not members of support group which is initiated by any NGO. Only 8.88% visited regularly to the monthly support group meetings of a Network.
24. Number of beneficiaries in legal literacy is very low.
25. 62% are not having knowledge about the difference between HIV and AIDS. Respondents who are not aware about opportunistic infections are 51.11%. 63(70%) respondent not know how the functioning of ART takes place. 54.44% respondents were well informed and also were aware about side effects of the ART therapy.

Testing of hypothesis

1. From the table no 2.35 the Chi-square value is 15.10, degree of freedom is 14 and Assy sig. is 23.69. here is chi square value is less than table value means accept null hypothesis , there is a relationship not existed between duration of treatment and psychological barrier.
2. In the table no 2.36 the Chi-square value is 25.7, degree of freedom is 14 and Assy sig. is 23.69. Here the chi square value is more than the table value which means reject null hypothesis, there is a significant relationship which exists between the duration of treatment and the social barrier.
3. Lack of networking with NGOs leads to low adherence, this Hypothesis is accepted.
4. Lack of Knowledge about HIV/AIDS among the respondent leads to low Adherence this Hypothesis is accepted.
5. Unawareness about importance of adherence of ART leads to low adherence this Hypothesis is accepted.

Conclusion:-

1. From the data

- Younger and more impulsive patients are more likely to forget or not prioritize taking their medications. Adolescent patients may be more easily distracted by issues of daily life. It seems this age group is more prone towards becoming HIV positive and are negligent, and are in need to be given more attention and more counseling.
- Male clients need more clinical and psychological counseling. Women are more concerned about their family and their children, that is why they take care of themselves, so the percentage is low.
- A lower level of general education and poorer literacy may have a negative impact on some patients' ability to adhere, while a higher level of education has a positive impact.
- Living alone and lack of support have been associated with an increase in sub-optimal adherence and social isolation is predictive of sub-optimal adherence. Not living alone, having a partner, social or family support, peer interaction, and better physical interactions and relationships are characteristics of patients who achieve optimal adherence.
- Hiding their status is by far the commonest reason for poor adherence by the clients. Some clients are extremely concerned that taking medications might inadvertently reveal their HIV status, and this can have a profound impact on their adherence. The fact that patient's family members may be useful to remind patients to take their medicines regularly, or to help them to pay for medicines, or both. Many PLHIV have a limited social support. In some cases, cultural or other factors may hinder the youth from disclosing their status to their families, and some youth may be estranged from their families as a result of a various of issues.
- Looking at our results however, trends were seen, though not significant, medication adherence was better with increasing numbers of family members. This may be due to the fact that patient's family members may be helpful to remind the patients to take their medicines regularly, or to help them to pay for medicines, or both.

- Stigma, discrimination, lack of family and community support are huge obstacles to ART adherence.
- Direct and indirect economic burdens borne by patients affect their ability to access a steady supply of antiretrovirals and to take them on time. Such burdens may include absenteeism from work, the cost of elders or childcare during hospital visits, the cost of transportation to a health center or being homeless.

2. From the observations:-

i) As it is observed that the respondents who had come to know about their HIV status and were put on the ART within a short period of time, the percentage of low adherence was high in them, as they had not yet overcome through the depressions of knowing their status and the related social problems.

ii) Greatest cause of discontinuation of the ART treatment is lack of support and migration. These two causes seem to be interdependent, because when there is no support from the family, the respondents are provoked to leave the house, which brings more depression and that becomes the cause of low adherence.

Further causes are also interlinked such as losing their daily wages and having no faith in the treatment. Actual reason is losing of wages, which creates the scarcity of money, which again leads to the depression even if the ART is provided free of cost.

iii) It is seen that as the ART therapy is having unpleasant side effects and is a well known fact among the respondents, it is also one of the factor for low adherence. Here if the client is well informed about the nature and complications of the ART therapy, it will also help them in achieving a healthy life even if there are some temporary problems.

iv) Adherence can be facilitated when a patient-provider relationship incorporates trust, good communication, adequate education about medications, and an overall perception of caring, including a culturally and linguistically appropriate approach to the relationship. Another quality of care is of crucial importance that is of maintaining a high ART adherence level.

v) Sociological problem and psychological barriers are interdependent which result in low adherence.

vi) Co-treatment of HIV and other infections remains a major challenge.

Interpretation is that the respondents who were undergoing co-management of HIV and TB did not adhere to ART and they mentioned pill burden as the major reason for low adherence.

vii) It is concluded from observations, that it is the tendency of human being is that, anything which is provided /got free of cost and without any labor cost, has less value for the individual. As medicine are provided free and unawareness about ART medicines cost, it leads to low adherence.

Suggestions:

1. NACO :

A) NACO should arrange orientation programmes, training and refresher courses, where in strategies, methodology and techniques for increasing adherence to treatment may be focused upon.

B) Clients should be charged for the first two doses of ART medicine when initiating the ART treatment to know the cost of medicine and create awareness about the cost.

2. Counselor :

For better adherence, health care providers should encourage the client to disclose the status to their spouses, near and dear ones and also the family members in order to get support from them.

The counselor must motivate the client by explaining them that tolerating side effects and having a healthy attitudes treatment will be beneficial to them in long run of life. Counselor should do counseling of the family members and the spouse so that they can be also a great help to the clients to take the treatment regularly.

The counselor needs to be well oriented and trained with more emphasis on the emotional aspect. Clients should be given time to cope-up with the depression if any, they may have and they should be mentally prepared for the treatment.

Counselor should try to fill the gap in the patient knowledge on HIV/AIDS, living with HIV infection, and ART. To check the knowledge ask them the basic simple question related treatment.

While taking session of preparedness tell the client that in the next visit they must be able to answer the counselors question to check mental reparedness and also assess the mental state to start the ART treatment.

A minimum of two counselling sessions are to be conducted before the start of the ART therapy.

3. ART Centre

The team and all other workers who interface with clients must be trained and sensitized to treat them with dignity. Health care provider should facilitate the clients in developing the network of supportive people or arrange the network to arrange peer group counseling at the ART centre which will make significant impact on adherence of the HIV therapy.

Appendix

A. INTERVIEW SCHEDULE

B. BIBLIOGRAPHY

Interview schedule

Topic :- “A Study of Psycho-Social Barriers of low Adherence in HIV Therapy and social work intervention with special reference

ART centre, Indira Gandhi Government

Medical College , Nagpur.”

Name of researcher :- Varsha Bhagat Research Guide :- Ms .R Bhabulkar
Confidential

Researcher is the student of M.PHIL Matru seva sangh, Institute of social work , Nagpur .The proposed study is being conducted as partial fulfillment of M.PHIL course. The information shared by you will be confidential and will be used only for the study purpose .

personal profile of respondent

Serial Number ;

ART registration no.

1. Age

- | | |
|-----------------|--------------------|
| 1. 15 to 24 yrs | 2. 25to 35yrs |
| 3. 36 to 45 yrs | 4. 46 to and above |

2. Sex

- | | | |
|---------|-----------|-------------------|
| 1. Male | 2. Female | 3. Transgender |
|---------|-----------|-------------------|

3. Education

- | | |
|--------------------------------|-----------------------|
| 1. Illitrate | 2. Primary |
| 3. Secondary /higher secondary | 4. Graduate and above |

4. Marital Status

- | | |
|-----------------------|------------------|
| 1. married | 2. Unmarried |
| 3 .Seperated /divorce | 4.widower /widow |

5. No.of children

- | | | | | |
|--------|--------|---------|--------------------|--------|
| 1.none | 2. One | 3 . two | 4. Three and above | 5. N.A |
|--------|--------|---------|--------------------|--------|

6 Are children staying with you?

- | | | |
|--------|---------|-------|
| 1. yes | 2. No . | 3.N.A |
|--------|---------|-------|

7. Types of family

- | | | |
|-------------------|--------------------|----------------|
| 1. nuclear family | 2. Extended family | 3.Joint family |
|-------------------|--------------------|----------------|

8. Employed

- | | |
|--------|-------|
| 1. yes | 2. No |
|--------|-------|

9. Occupation

- | | | |
|--------------------|---------------------|-----------|
| 1. Skilled labour | 2. Unskilled labour | |
| 3. Private service | 4. Govt. service | 5.Nothing |

10. Monthly income of the respondent

- | | |
|----------------|-------------------|
| 1.below 1000 | 2.1000 to 2000 |
| 3.3000 to 4000 | 4. 4000 and above |

11. Ownership of house

- | | |
|--------------|-----------------|
| 1. Own house | 2. Rented house |
|--------------|-----------------|

12. Is family in any kind of debt .

- | | |
|--------|---------|
| 1. yes | 2. No \ |
|--------|---------|

13. How the debts are incurred ?

- | | | | |
|---------------------|---------------|----------------------------|-------|
| 1. helping relative | 2.Taking loan | 3.Selling ancient property | 4.N.A |
|---------------------|---------------|----------------------------|-------|

14. No .of years HIV status known

- | | |
|-------------------------|----------------------|
| 1. less than one year | 2. one to three year |
| 3. more than Three year | |

5. HIV status known to

- | | | | |
|-----------|--------|---------|-------|
| 1. spouse | 1. yes | 2. No . | 3.N.A |
|-----------|--------|---------|-------|

2. Closure family member 1. Yes 2. No .
3. one or more Neighbour /friends 1. yes 2. No .
4. one or mor friends 1.yes 2.No
5. Working place 1. yes 2. No .
16. what is your spouse status
1.HIV positive 2. HIV negative 3.Unknwon 4.N.A
17. What are spouse attitudes towards you after knowing status.
1.symphatic /pity 2. Indifferent
3. pessimist towards patient 4.optimist towards patient 5.N.A
18. What changes occurs in the behavior of spouse after knowing status
1. spouse left home 2. Angry /frustrated
3.more caring 4. N.A
19. What are relatives attitudes towards you after knowing status.
1. symphatic /pity 2.Indifferent
3. pessimist towards patient 4.optimist towards patient 5.N.A
20. What are behaviour changes in the relatives when came across your status
1. Stopped to visit home 2. Not invite in the function
3. Not speaking 4. No change in the behaviour 5.N.A
21. What are friends attitudes towards you after knowing status.
1.symphatic /pity 2. Indifferent
3.pessimist towards patient 4.optimist towards patient 5. N.A
22. What are the behavioral changes in the friends after knowing status
1. totally cut relation 2.low frequency of visit
3. No change in the behaviour 4.N.A
3. What are neighbor attitudes towards you after knowing status.
1.symphatic /pity 2. Indifferent
3.pessimist towards patient 4.optimist towards patient 5.N.A
24. What are the behavioral changes in the neighbors after knowing status
1. totally cut relation 2. low frequency of home visit
3. Not attending the function 4. No change in the behavior 5.N.A
25. Any discrimination face in the employment place after knowing status
1.No change in the behaviour . 2.not sharing food
26. Do you know difference between HIV/AIDS?
1.yes . 2. No 3.Cant say
27. Are you aware about opportunistic infection ?
1.yes 2. No ,
28. At present any opportunistic infection do you have ?
1.yes 2. No
29. Which opportunistics infection do you have ?
1. Pulmonary tuberculosis 2. Extrapulmonary tuberculosis
3. Herpes Zoster 4. Candidisis 5.Diarrhoea 6.N.A
30. Do you do regular CD 4 counts
1.yes 2. No
31. What is last CD4 count ?
1. Between 1to50 2. 50 to 100
3. 100 to 150 4 150 to above
32. Do you believe in HIV therapy ?
1. fully believe . 2 to Some extent 3. Not believe
33. Do you know function/effects of ART in our body ?

- 1.yes . 2. No 3.cant Say
34. Do you aware about importance of adherence of ART ?
1.yes . 2. No 3. Cant say
35. Duration of starting ART therapy?
1. less than one year 2. 1 year to three year
3.more than three year
36. Are you satisfied with your health after starting ART
1. Dissatisfied 2. satisfied 3. cant say
37. Which strategy used to remember to taking dose ?
1.Pill diary 2. Calendar
3. reminds Spouse /family member 4. alarm 5.Self remind
38. Did you suffer from any side effects when initiated ART therapy?
1.yes . 2. No
39. If yes, which side effects you have ?
1.Anemia 2. Skin rash 3. Peripheral neuropathy
4. nausea/vomiting 5.lipodipathy 6. Loose motion
7.Dizziness/ insomnia /nightmare, suicidal ideation
8.N.A
40. Did you had any prior information about side effects and its management
1.yes . 2. No
41. Do you miss any ART dose ?
1.yes . 2. No
42. What is frequency of missing dose ?
1. Single dose 2. More than 2 days
3. More than 15 days 4. More than 3 in a month
43. What are the causes which give rise to the psychological problems responsible for missed dose of ART
1. depression/stress after knowing status
2. Fear of Side effects of ART
3. Recurrence of Opportunistic infection
4. Pill burden .
5. Differences with spouse or family member
6. Depression due to Lost of /partner and living alone
7. Addiction of Alcohol and substance
8. Change in daily routine life style
44. Do you face following Social problems which is cause to discontinue the ART treatment
1. Social stigma ,fear of disclosure HIV status
2. ,limited faith in the treatment .
3. Lack of family and social support
4. Financial constraints/travel costs
5. Migration and frequent traveling for employment
6. Loosing daily wages
7. Not getting leave from working place
8. Just forget -----.
45. Any difficulties did you face in ART centre to continue the ART treatment ?
1.yes . 2. No
46. Which type of difficulties did you face to continue the ART treatment
1. time consuming

2. Not basic facility available in ART center
3. fear of recognition HIV status in ART centre
4. N.A
47. Are you member of any support group of any organization
 1. yes .
 2. No
48. If yes, this group is initiated by
 1. Network of Nagpur people living with HIV(NNP+)
 2. Positive women network of Maharashtra (MPWN+)
 3. Religious organization
 4. Any other NGO
 5. N.A.
49. Frequency of visit to meeting in peer group /Support group . .
 1. Almost daily
 2. Once in a week
 3. Once in month
 4. Rarely
 5. N.A
50. Duration of membership with support group /network
 1. less than 3 month
 2. 3 to 6 months
 4. 6 to 12 months
 4. 12 month and above
 5. N.A
51. What kind of social support provided from Network//organization.
 1. home Visit by member
 2. help in the illness.
 3. help to get in admission in hospital.
 4. N.A
52. Which type of Emotional support provided from Network//organization
 1. Counselling
 2. sharing the experience
 3. companionship
 4. hope/motivation
 5. N.A
53. What kind of Legal support provided from Network//organization
 1. provide information about Human rights /health rights
 2. provide information about Right to Information./PIL
 3. support to fight in the legal matter.
 4. N.A
54. Which type of Economical support provided from Network//organization
 1. Provide nutrition/rationing
 2. Giving information about financial resources
 3. Training of Income Generating Programme
 4. N.A.

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